

A cross-sectional survey of people with stroke, their family members and Multi-Disciplinary Team (MDT) health professionals regarding the value of the information book *Life after Stroke: a Guide for People with Stroke and Their families*.

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Dedication

To my husband, Buddha Thapaliya, my mother Sangita Prasain, and my in-laws Durga Prasad Thapaliya and Bishnu Devi Thapaliya

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Abstract

Life after Stroke: a Guide for People with Stroke and their Families is a book first published by the Stroke Foundation of New Zealand in 1998, reprinted in 2004, with a second edition published in 2013. The book was produced to meet the information needs expressed by stroke survivors and their family members. The book provides information about stroke, its impact, and implications on stroke survivors' lives. The book is available in both hard and soft copy format. People with stroke and their families are given this book in hospitals and in the community.

The aim of the thesis is to ascertain the value of the book *Life after Stroke: a Guide for People with Stroke and their Families*.

A cross-sectional survey was used with people with stroke, their family members/caregivers, and health professionals to determine the value of the information book *Life after Stroke: a Guide for People with Stroke and their Families*. The survey was designed to see how the patients and their family members found the book in regard to ease of reading/understanding, accessibility, usefulness, and value. Two sets of questionnaires were developed: one for health professionals and another for stroke patients and family members/caregivers. The study was undertaken in a stroke rehabilitation ward. The data collection period was from June to October 2016. Data analysis was done using the computer program SPSS.

The study reported two thirds of participants (50/75) have read the book. Among them 14 were patients, 12 were family members/caregivers, and 24 were staff. Seventy percent of the participants who rated the book found the book was very useful with only 2% of participants reporting it was not useful. Eighty-three percent of participants thought the book had the right amount of information, 91% of respondents felt the words and sentences in the book were easy to understand,

and 93% of respondents felt the size of the letters in the book were easy to read. As a result of reading the book 73% (19/26) of respondents felt they had a better understanding of their role in rehabilitation, 14 felt they became more knowledgeable, and 12 felt more confident in rehabilitation. Two thirds of participants were not aware of the existence of an electronic version of the book and 90% participants (patients and family members/caregivers) preferred to read paper resources.

Although the book was meant to have been distributed to the survey participants, just over a third (39%) of respondents reported that they had not received a copy of a book. The reason behind this included: staff reported that they did not know about the book or where the books were kept, were not involved in admission process because they are casual staff, believed that it was not their job to distribute the book and patients and family members never asked them for a copy of the book. Staff who had worked longer in their role were more likely to distribute the book compared to new staff members.

Although most people considered that the book was very useful, still half of the participants reported that the book could be presented in different formats, such as on television screens in the hospital and at General Practitioners (GP) practices, as posters, at a social group meeting, on a CD (talking book) or by a person reading the book to patients. Participants also suggested some areas to improve the book, such as being shorter and producing a simplified version, provide more information about stroke clubs, and what they offer, information about grants and financial assistance, diagrams to demonstrate different recovery stories associated with different types of stroke, to break the book into tabulated sections, and to include pull out sections.

In conclusion, the study was able to find the book *Life after Stroke: a Guide for People with Stroke and their Families* was valuable to stroke patients and their family members. However,

still some development is needed to make the book more accessible and valuable. This can be done by providing training to staff about who is the responsible person to distribute a book and where are they kept and by editing the book considering the feedback from stroke patients, their family members and the health professionals working in the stroke ward.

Glossary of terms

| | |
|---------|--|
| ADL | - Activities for Daily Living |
| CDHB | - Canterbury District Health Board |
| CD-ROMs | - Compact Disk Read-Only Memories |
| DHB | - District Health Board |
| DVD | - Digital Video Disk |
| GP | - General Physician |
| ICU | - Intensive Care Unit |
| IDT | - Inter-Disciplinary Team |
| KTT | - Knowledge Transfer Team |
| MDT | - Multi-Disciplinary Team |
| NHS | - National Health Service |
| OPHSS | - Older Person's Health Specialist Services |
| PDF | - Portable Document Format |
| REALM | - Rapid Assessment of Adult Literacy |
| SAM | - Suitability Assessment of Materials |
| SPSS | - Statistics Software Package for Statistical Analysis |
| UC HEC | - University of Canterbury Human Ethics Committee |
| US | - United States of America |
| UK | - United Kingdom of Great Britain and Northern Ireland |

Chapter 1 Introduction

1.1 Stroke

A stroke is caused by the interruption of blood supply in the brain generally due to blood vessels bursting or blood vessels being blocked by a blood clot in the brain. According to “Inter-Disciplinary Team Self-Learning Package” (2016) there are two main types of stroke: namely ischaemic and haemorrhagic.

Ischaemic Stroke: - This is the most common stroke and occurs in 85-90% cases in which blood clots block an artery. This can be either embolic or thrombotic. Thrombotic stroke occurs when the thrombus (blood clot) blocks an artery which was narrowed by fatty deposits. Embolic stroke occurs when a clot, which is formed outside the brain, goes through blood to the brain and blocks the arteries (Southern Cross Healthcare Group, n.d.).

Haemorrhagic Stroke: - This stroke is less common but it has severe effects. It is caused by either by high blood pressure or other arterial factors such as weekend artery that balloons out or an arteriovenous malformation (Southern Cross Healthcare Group, n.d.).

The effects of stroke vary upon the damage and which side of the brain is affected (Stroke Foundation, n.d.). They are:

Effects of stroke when the right side of brain cell is damaged

- Loss of left side power, feeling, vision, and awareness
- Excessive talking or slurred speech
- Difficulty in swallowing or eating and interpreting sounds
- Difficulty in recognising familiar faces, seeing how things relate to each other in space
- Denying existence of problems, depression

- Tendency to sarcasm, short concentration, and memory problems
- Poor judgement of physical abilities and difficulty with thinking and acting without thinking
- Mood swings and lack of interest

Effects of stroke when the left side of brain cell is damaged

- Loss of power, feeling, awareness, and vision on right side of the body
- Difficulty with speaking and not understanding what other people are saying
- Poor motivation, not able to read and write, thoughts disconnected, and verbal memory loss
- Difficulty to perform purposeful movements
- Confusion between left and right, easily frustrated
- Difficulty with structuring and planning behaviour and dealing with numbers

Effects of lower back part brain damage

- Balance and co-ordination problem and abnormal head and upper body movement
- Dizziness, hiccups, nausea, and vomiting

Effects of Brain Stem cell damage

- Nausea, vomiting, or difficulty in swallowing
- Drowsiness, loss of movements, and sensation in both side of body and coma or disturbed alertness.

Annually in the world, 15 million people experience a stroke. Of them, 5 million die and another 5 million are left disabled (World Health Organisation [WHO], n.d.). Stroke is the second leading cause of death above 60 years age and fifth leading cause in population 15-59 years old (World

Heart Foundation, n.d.). One of the non-modifiable risk factors for stroke is age. Half the number of strokes occur in people over 75 years. Up to age 75, the incidence of stroke is higher in men compared to women of the same age and the same in the age group 75-84 years. But, the incidence is higher in women than men in the age group greater than 85 (Falcone and Chong, 2007).

According to Southern Cross Healthcare Group (n.d.), in New Zealand, stroke is the third largest cause of death and the greatest cause of disability. Every year in New Zealand, approximately 8,000 people have a stroke. Approximately 25% of people, who recover from a stroke, go on to have another stroke (Southern Cross Healthcare Group, n.d.). According to the Stroke Foundation of New Zealand (2015), every year 2,500 people are dying after a stroke and about 10% of deaths occur in people under 65 years of age. There are approximately 60,000 stroke survivors living with a range of impairments and these people need significant assistance for their Activities for Daily Living (ADL) requirements (Stroke Foundation of New Zealand, 2015).

Stroke in Māori

Māori are at high risk of having a stroke and dying compare to non-Pacific and non-Māori in New Zealand (Robson and Harris, 2007). Māori are also younger, on average, at the onset of the first stroke than New Zealand Europeans; however, there is an association with additional issues to having a stroke at a young age for Māori, such as loss of income (due to unemployment) and reduced social support. (Daniel, Wolfe, Busch, & McKevitt, 2009). According to Stroke Foundation of New Zealand (2015) the rehabilitation options for Māori are also limited due to different causes for example, the person who is assisting the person with the stroke is themselves not able to drive, or there is limited to access retraining (Fink, 2006). Furthermore, access to rehabilitation services and funding for people aged under 65 years is restricted (Fink, 2006). Stroke information is also an issue for Māori and their family as there is still a lack of co-ordination,

difficulty in understanding, and information as the stroke service providers are with different backgrounds, are unaware about Māori culture and are not aware about the health information delivery method (Harwood, 2005). Māori people get difficulties in understanding due to the poor health literacy of Māori while comparing with non-Māori, Māori prefer to receive verbal information along with written information (Ministry of Health, 2010). There is also an expressed concern from all Māori stroke survivors, along with their caregivers, that they are being given limited information which would assist them to understand stroke recovery process. Because of this lack of information they are facing difficulty in identifying how are they doing in rehabilitation process (Dyall, Feign, Brown, & and Roberts, 2008).

Stroke in Pacific people

Like Māori, Pacific Islanders also experience stroke in high rates, in comparison with other New Zealanders and the rate of death of Pacific Islanders who have a stroke was over two times the mortality rate of other New Zealanders for the same period (Blakely, Tobias, Atkinson, Yeh, & Huang, 2007). Risk factors such as hypertension, diabetes, smoking, and obesity are associated with the higher incidence of stroke among Pacific people (Fink, 2006). There is improvement that Pacific Islanders are benefitting from hospital stroke care since 1981; however, effort is needed to reduce disparities in stroke results for Pacific people by prioritising primary prevention and community rehabilitation in stroke care (Stroke Foundation of New Zealand, 2010).

In New Zealand in recent decades, there has been a reduction in the overall incidence of, and death because of, stroke. However, a significant decrease in stroke incidence is seen only in New Zealand European population. There has been no decrease in the incidence of stroke in Māori and the incidence of stroke has increased in Pacific people (Carter et al., cited in Stroke Foundation of New Zealand, 2010). According to the Stroke Foundation of New Zealand (2010), there are still

noteworthy disparities between Māori and non-Māori in the prevalence of risk factors for stroke, stroke incidence and mortality rates, and access to stroke care and stroke outcomes. The number of deaths from strokes in New Zealand has not changed at all because, in general, the decrease in overall age standardised death rate for stroke over the last 20 years has been balanced by the ageing of the population (Ministry of Health, 2009). The total number of stroke patients aged over 65 years admitted to stroke rehabilitation ward (Ward DG/2A) during the data collection period June 2016 to October 2016 was 90. Among them four came from rest homes, six came from retirement homes from independent units, and the remainder came from private homes. Of the 90 patients, 47 patients were able to return home following rehabilitation whereas 40 patients were referred to rest home care, and three patients died.

1.2 Continuum of Stroke Care

Rapid, early assessment, and management is done in acute care. The principal of rehabilitation should be applied in acute and post-acute setting (Stroke Foundation of New Zealand, 2010). According to the Stroke Foundation of New Zealand (2010):

rehabilitation is a proactive, person-centred and goal-oriented process that should begin the first day after stroke. Its aim is to improve function and/or prevent deterioration of function, and to bring about the highest possible level of independence – physically, psychologically, socially, and financially.

Rehabilitation is not only concerned with personal improvements, it is also assisting with resumption of meaningful life roles and reintegration in the society where they live (Stroke Foundation of New Zealand, 2010). Rehabilitation for stroke patients should be started from the first day with the effort of service providers (Stroke Foundation of New Zealand, 2010). Specialised Inter-Disciplinary Team (IDT) members coordinated programme provision is the central aspect in rehabilitation and recovery of stroke patients. The IDT team includes doctors,

nurses, physiotherapists, occupational therapists, speech language therapists, dietitians, social workers, psychologists, and pharmacists (Stroke Foundation of New Zealand, 2010). This team provides coordinated and combined care of medical, allied health, and nursing care with social, vocational, and educational services. In addition, IDT members also do assessments for the regular review of treatment, discharge plans, and follow-up. The issues that are considered by people with strokes are important to their community. Care and support services are also important (Stroke Foundation of New Zealand, 2010).

1.3 The Stroke Foundation of New Zealand

The Stroke Foundation of New Zealand is a non-profit organisation established in 1981, which works with the Stroke Foundation of Australia and New Zealand, to reduce the incidence of stroke and to improve outcomes for those who have had a stroke. Funding for the Stroke Foundation of New Zealand is provided by Ministry of Health. The main purposes of the Foundation are to save lives, improve outcomes, and to enhance life after stroke. The Foundation seeks to reach its goals by educating people about strokes, its risk factors, signs and symptoms, and promoting to the public healthy life styles. The Foundation also works with health service providers to improve accessibility and delivery of optimum quality stroke services. In addition, the Stroke Foundation also provides information services and community based support (Stroke Foundation of New Zealand, 2010).

1.4 History of the book

It is normal for the stroke patient to feel shocked, frightened, or unable to think clearly when a stroke has first occurred (Stroke Foundation, n.d.). It is also upsetting for the family members to see a once capable loved one not being able to do the simplest task without help, not able to talk, being frustrated, and struggling while rehabilitating. Family members may get frustrated

themselves and it may become difficult to continue with their daily activities such as going to work, looking after their children, and many other things. Similarly, they may also blame themselves for not noticing vague signs predictive of a stroke earlier (Stroke Foundation, n.d.). As a consequence of noticing these difficulties, the Stroke Foundation published a book *Life after Stroke: a Guide for People with Stroke and their Families* in 1998. This book provides information about stroke, its impact, and the implications for stroke survivors' lives. This book is available in both hard and soft copy formats (Stroke Foundation, 2004). One of the roles of health professionals in the rehabilitation ward is to provide information to patients and their family members and caregivers so that they can better understand what is going on and what they are supposed to do (Butow, Brindle, McConnell, Boakes, & Tattersall, 1998). The Canterbury District Health Board (CDHB) stroke rehabilitation ward also provides the book and CDHB stroke information resources (pamphlets which contain information regarding stroke) to patients and their families to educate them about what a stroke is, what it may feel like after a stroke event, what will be the best thing to do at that time, and how the patient can participate in rehabilitation.

1.5 Background of the problem

Stroke has various consequential effects such as problems with mobility, bladder and bowel function, swallowing, vision, and communication. It can also affect the person's emotional state and may lead to depression, anxiety, or personality changes. Ongoing effects from a stroke can have a significant impact on the patient's life. It is a serious and sudden condition and it is upsetting to see someone in this situation especially when family members of stroke patients do not know what has happened nor what they can do to help (Stroke Foundation, n.d.). The family of those who have a stroke feel that it is an important life event: the former life is lost, there is guilt, family life turned upside down, life is restricted, roles and relationships have changed, and the family

foundation shaken (Fischer, Roy, Niven, & Tyrrell, 2014). The hardest time felt by carers of stroke patients is during hospitalisation and a month after discharge due to newly added responsibility, uncertainty, emotions and impairments, lack of information and skills to handle patients, and a lack of confidence (King and Semik, 2006). According to a review by Camak, (2015), the duty of family caregiving is a burden and most of the caregivers are not prepared to bear the responsibilities to provide continuous care to their family, many caregivers are senior people with a range of different health needs of their own. Camak found that caregivers have information and educational needs which include physical care, diet, safety, medicine administration, safety with transfer. According to Camak research has also shown that many caregivers hesitate to ask questions. Providing accurate, adequate, timely, and situation specific information is recommended as an important part of care provision (Forster, Smith, Young, Knapp, House, & Wright, 2001). According to National Health Service (NHS) Shetland (2010) in this situation health information given to the patients and family members can bring about very positive changes. Research has shown that the patients provided with information regarding tests and treatments are more satisfied and less anxious than those who are not given information. In many instances, patients are reluctant to raise questions during a consultation. Health professionals can encourage patients to ask questions by providing written information (Grime, Raynor, Pollock, & Knapp, 2007). According to McKechnie, Hach, Roy Harrington, & Anderson (2016) the stroke family/whanau project was run with the collaboration of Waitemata District Health Board and has been ongoing from 2010. On phase one (2010-2011) the project surveyed family of stroke survivors and health professionals to find education and information needs by finding out the current resources and practices, accessibility, the appropriateness, timeliness and gaps in information. In phase two (2011-2015) qualitative study was done to know the experience of

families who have stroke patients. The preliminary findings of phase one and phase two of the stroke family/whanau pilot project indicated that improving education support and outcomes for the family will lessen the burden of stroke on people and the community (McKechnie et al., 2016). One of the important parts of counselling people with stroke and their caregivers is providing appropriate quantities of verbal and written information. Health professionals working with those who have had a stroke should be aware of their importance as information providers and they should have access to information resources to distribute. Apart from providing information, health professionals also play an important role in stimulating patients and caregivers to ask for and to find information (Wachters-Kaufmann, Schuling, The, & Meyboom-de Jong, 2005). Patients and caregivers might get motivated to contact doctors and nurses in the journey of patient care and help them to find the problems and seek help (Panfil, Fuchs, & Willems, 2007). According to Ostwald, Godwin, Cron, Kelley, Hersch, and Davis (2014) approaches like providing information, skilful training, and counselling assist in the improvement in the health of stroke victims and their family/caregivers. Ostwald et al. (2014) also stress that depression levels decrease in stroke survivors with interventions like mailing information. The study also suggested that high-quality information provision and maintaining relationships with people, who have had a stroke and their caregivers, increases the health status of survivors and their families. If the information book and leaflets are distributed frequently there is noteworthy improvement in stroke knowledge in the community (Morimoto et al., 2013). Patients receiving information felt it was easier to expect what is going to happen in the recovery journey and that information also helps to cope with life style changes (Tooth and Hoffmann, 2004). According to the Stroke Foundation of New Zealand (2010) in Auckland (24 June 2010) a consumer forum was coordinated and facilitated to provide feedback from consumers to the New Zealand Guideline Reference Group and the main

focus was on rehabilitation and life after discharge from hospital. At the forum consumers listed ten vital things they wanted stroke services to help them to achieve:

- “optimum recovery through ongoing rehabilitation
- maximum independence (return home, resolve family/*whānau* issues)
- participation in leisure activity
- return to work (including understanding/empathy from employers)
- ability to drive again
- community support (support groups)
- support for spouses/caregivers (psychosocial and financial)
- ready access to information about stroke in plain language and at a level for consumers
- overcoming language/communication barriers (especially where English is a second language)
- achievement of goals and aspirations”.

From this also we can see one of the important needs that people feel more is information is needed.

Information sharing can be through face to face talking or through providing written health information resources. Health information plays a great role in the management of chronic and complex diseases such as hypertension, asthma, angina, and peptic ulcer. The long-term management of such diseases involves self-care by the patient (Morris and Halparin, 1979). Stroke survivors interact with different services in the journey to recovery. For example, the person moves

from primary care to specialist acute stroke services, and from there to specialist rehabilitation services, and then to social services (such as housing). One of the recommendations is that during this journey the organisation should make sure that all relevant information is transferred, the stroke survivor should be offered written copies of information, advice, and support (Royal College of Physicians, 2016). According to Wachters-Kaufmann et al. (2005), about 90% of patients and caregivers read written the information guide and the most frequently read chapter is on the medical issues. According to the National Stroke Foundation (2010) people with strokes and their caregivers should be given information about the benefits of local stroke support groups and other resources such as peer support. Information needs to be in a range of languages and formats, which can be readily understood, and these should be offered repeatedly. Written information can be provided by the Stroke Foundation to use as a part of comprehensive education programme (National Stroke Foundation, 2010). Although it is easy, quick, and spontaneous to provide verbal information, which health professionals do quite often, there is a drawback that the patients may not properly understand and recall it (Wilson, Robinson Blenkinsopp, & Panton, 1992). Written information can be very valuable because it ensures consistency, stimulates questions, and aids memory (O'Connor et al., 2009). To increase a patient's participation in, and understanding about their medical condition, finding out about the patient's opinion about information leaflets has become routine in medical and surgical practices. Both inpatients and outpatients expect to be kept well informed about their diagnosis, investigations, and treatment options (Harvey and Plumridge, 1991; Humphris and Field, 2003). To meet these expectations, the provision of information should be in the right format for patients to understand it. In previous studies, it was shown that patients welcome written information because it assists in their understanding, and it aids in decision making (Rogsted et al., 2003).

The patient's need for information may not be satisfied by what experts have decided (Turnbull, 2003). There are many differences between the desired and the actual information that is provided. Information needs have not been met by actual provision information (Wachters-Kaufmann et al., 2005; Gustafsson, 2008). Many studies have already shown that patients were not able to manage their diseases because they did not receive the necessary information (Morris and Halparin, 1979). Sometimes written information, the major tool to provide information, can be irrelevant, volatile, and incomprehensible (Foster and Rhoney, 2002). Poorly designed information will not be beneficial and will be misleading, and furthermore it can make the patient more confused (Knapp, Wanklyn, Raynor, & Waxman, 2010). According to Gustafsson (2008) the information that is provided cannot meet the information needs if its presentation is poor. If we provide information we also need to ascertain its value. Only then we can know if it is really useful to the consumers or not, and if not, what is missing? If evaluations of health consumers' needs are not conducted, then the teaching aids which are ineffective will not be identified and the learning needs of patients' and their family members will not be met. Furthermore, feedback from health consumers will be valuable because it can be utilised to modify and to revise teaching aids so that consumers learning needs can be met (Parrinello, 1984). To revise the health information document, testing is necessary and experts are not good at finding problems that the reader will face (Lentz and DeJong, cited in Knapp et al., 2010, p. 367). To test the understandability of a health information book research should consider the clinical setting. Recruiting respondents with no experience of stroke meant that acquired knowledge was attributable primarily to the book (Knapp et al., 2010). According to Turnbull, (2003) to create good information tools, six elements can be helpful. They are:

- listening to the patient,

- having a clear purpose,
- providing good information,
- undertaking clear writing,
- having good readability and
- eliminating fear.

A major role of health professionals is to listen to patients, caregivers, and family members and to include these six elements. Some patients and family members may have had bad experiences and those patients and family members may want future patients not to have the same problems (Turnbull, 2003). Because of this, research can explore such experiences and recommend new approaches to be adopted.

According to Roy, Gasqoine, Caldwell, and Nash (2015) Multi-Disciplinary Team (MDT) members have a great role to play in the stroke trajectory in terms of helping to alleviate the stresses felt by family and patients. Although staff are aware about the provision of health information, implementation is not good for a variety different reasons in the work place along with work team barriers (Gustafsson, 2008). According to Hanger, Walker, Paterson, McBride, and Sainsbury (1998) despite the policy of providing written information to people who have had a stroke basic questions still remain. According to their research possibilities of this failure of education are:

1. the information was given at a time of stress and thus not retained
2. the information given was not understood or was misinterpreted
3. concentration and memory deficits resulted from the stroke itself, leading to impaired retention of new material

4. information is heard but the patient is still adjusting emotionally

5. health professionals have not provided stroke education despite the policy.

One of the strategies for distributing and communicating health information would be to think about what training for health professionals (who distribute the information material) is required so that the information book will be distributed properly to the people who need it (New Zealand Ministry of Health, 2012). My research project will be helpful in determining if the *Life after Stroke* book is being distributed by health professionals to the appropriate patients and family members, or not, and whether it is given at the right time. It will explore if patients and family members know where they can find the book and if they want changes made to the content or format of the book.

Lupton (cited in Dutta-Bergan, 2005) noted that there is top to bottom approach in communication in the health sector – from the centre of authority to peripheral locations. If the power is central it is difficult to find the problems and solutions (Wilkins and Mody, 2001). The *Life after Stroke: a Guide for People with Stroke and their Families* book was based on the information sought from various stakeholder groups with stroke patients, family members, and health professionals, who provide care for stroke patients, each contributing their expertise and experiences. Since its last publication, there has not been any research conducted on how the patients, family members, or health professionals feel about its usefulness. The second edition was published in 2013 (<http://www.stroke.org.nz/store/life-after-stroke>) without further input from patients and family members. The second edition is the version used in this research.

One of the important components of the care for people with stroke and their carers is the provision of stroke information (National Stroke Foundation, 2010). Meade (n.d.) has stated that although

presenting content, the educational material developer should see the patient as a whole, and focus on the health team providing the information rather than discipline specific information, highlight the importance of patients, families, friends, and on culturally appropriate language. But, these information needs are not met properly (Eames, Hoffmann, Worrall, Read, & Wong, 2013).

Today, many things are changing. The first challenge is that people aged 65 years and over are increasing in numbers as life expectancy increases. It is predicted by 2026 that one in every five persons will be over 65 years of age and the over 85 years of age population will double in size. The demand for District Health Boards (DHBs) to deliver health services to this ageing group in society will, therefore, increase (CDHB, n.d.). The second challenge for New Zealand is maintaining a fit for purpose health workforce. In New Zealand, it is becoming harder to retain the health workforce. According to the Association of Salaried Medical Specialists (2014), the workforce registers show that specialists are either leaving the profession or migrating to other countries. Among the registered GPs 37% are no longer practising in New Zealand a decade after first registration. There is also a workforce issue in nursing according to Ministry of Health, (2016). Nursing is considered as an ageing profession where the average age of nurses is 46.3 years, which is up from 45.9 in 2009. Table 1 shows the nursing workforce (age 50+) statistics.

Table 1 shows the ageing nursing workforce (age 50+) statistics.

| Nursing workforce* | | | | | |
|--------------------|------------|------------------------------|---|---|--|
| Size | Age 50+ | Gender split | Ethnicity | Main place of employment | Qualified outside New Zealand |
| 52,729 | 45.2% | Female 91.4% Male 8.6% | European/Other 74.3% Māori 6.5% Pacific 2.6% Asian 16.6% | DHB employed 51.3% Primary health organisation 12% Other 36.7% | 26% |

Table.1: Ageing Nursing workforce (age 50+) statistics * Nursing Council of New Zealand end of year statistics as at 31 March 2015. (Ministry of Health, 2016)

Another issue stated by the Ministry of Health, (2016) is as the economic status of nurses improves there is a tendency for nurses to leave the New Zealand nursing workforce, either leaving the profession, or moving to other countries, such as Australia, for employment. This trend is going to put pressure on the forthcoming supply of nurses. According to the Stroke Foundation of New Zealand (2010) another issue is service accessibility. Service accessibility is one of the main barriers for the provision of equitable services and this is prejudiced by different things such as geography, spiritual beliefs, and culture. In rural and remote areas, it is challenging to provide services because of limited human resources. Because of this people living in rural areas may

experience difficulty in accessing health care compared to urban areas (Stroke Foundation of New Zealand, 2010). In this situation, it is hard to educate patients and family members by only using health professionals. In addition, many elderly people have different impairments in body systems due to different disease conditions together with the ageing process. This is making difficult for elderly people to read and write due to vision-related disease. This may mean that elderly might want the information material displayed and available in a different format.

Although health information books have been published, there is uncertainty as to whether consumers are aware of their availability or whether the books are being appropriately distributed. The first edition of *Life after Stroke: a Guide for People with Stroke and their Families* (1998) was available only in paper format but, now the second edition is available in various formats, including on the Internet. Internet use, to get health information, is increasing in all age groups (Kerr, Hilari, Litosseliti, 2010). According to Nasmith and Parkinson (2008) there are several advantages of Internet based health education. They are: -

Reading materials can be delivered soon, no need to be in a waiting list

Sound quality could be better in the player

Health consumers do not need to depend on others

Requested books and magazine can be downloaded automatically

Despite of needing power socket book and book player can be moved in any corner of house as it has wireless connection.

There may be difficulties for a library to provide services to the increasing numbers of senior citizen who are also suffering from age-related disorders such as aphasia, vision impairment, hearing impairment, and the like. At this time, electronic books and audio CDs could be of great help (Nasmith and Parkinson, 2008). The perception that ageing people are reluctant to change has not demonstrated by the trial by the Royal New Zealand Foundation of Blind (RNZFB) pilot project (Nasmith and Parkinson, 2008).

Are the MDT members, patients, and family members aware of the electronic version of the book or not? There are many questions, so to find the answers to such questions a survey of stroke patients, family members, and MDT members is the task of this research. An appropriately used information book will save the time of health personnel in communicating health education to the stroke patient and family. The information book can cover all the answers to important stroke related topics and it can also help the stroke patients and family members to recall the education given by the health professionals. So, hopefully, it can also help to make understanding the message quicker.

All the efforts of mutually disparate sub-disciplines of group communication, organisational communication and interpersonal communication need to be integrated by a health communication campaign (Dutta-Bergan, 2005). New Zealand is well known for being at the forefront of using information to support cost-effective health and disability services, which is excellent because it helps to meet emerging challenges such as the rising incidence of chronic disease and the ageing population (King, Health information strategy Steering Community, 2005). To maintain this reputation, the quality of the information provided by each medical profession and organisation should be of the highest standard. Patients and family members can be useful in developing information books that can enhance the quality of information (Rodgers, Atkinson, Bond, Suddes,

Dobson, & Curless, 1999; Paul, Hendrey. & Cabrelli, 2004). To provide accurate and trustworthy information for patients and carers, the Stroke Association UK ask stroke survivors and medical experts to help to put information together. (Stroke Association UK, n.d.). The principles for dealing with feedback are, first the comments and suggestions are dealt with to address the errors and points for clarification. After that if amendments are needed all feedback should be recorded, actioned, and resolved (NHS England, n.d.). The time that health care providers have could be used in other productive activities if patients and their caregivers can be prompted to use health information resources because it can reduce the demands on health care providers' time (Wagner, Hu, & Hibbard, 2001). Because of this, the current research is important to help to equip the stroke patients and their family members with appropriate knowledge through the information book *Life after Stroke: a Guide for People with Stroke and their Families*. This reduces the time of health professionals on this task, which can be used to look after many other patients.

The study was based in Ward 2A/DG, the stroke rehabilitation unit, for patients over the age of 65 years in the CDHB catchment area. The stroke patients are referred to the ward from the Christchurch Hospital and over the duration of the study, the ward was relocated from The Princess Margaret Hospital to Burwood Hospital. The Princess Margaret Hospital /Burwood Hospital Ward 2A/DG was chosen for study because, approximately 75% of the people who suffer from stroke are over the age of 65 years (Stroke Foundation, n.d.). In the ward stroke patients are assessed as to whether they are able to go home and live independently, or not, after rehabilitation, and some patients will be referred to the community stroke team, the Stroke Foundation, or Nurse Maude as necessary. The *Life after Stroke* book has a great role in this setting as patients who have recently been diagnosed with stroke experience shock and find it hard to cope with their situation. Thus, Ward 2A/DG was selected as a fitting location for evaluation of this health information book.

1.6 Study aims

1.6.1 Aim of the book *Life after Stroke: a Guide for People with Stroke and their Families*

The aim of the book is to guide stroke patients, their carers, and their family through the challenge of coming to terms with the physical, mental, and emotional changes that having a stroke can bring.

1.6.2 Aim of the research

The main purpose of the research is to find whether the information book *Life after Stroke: a Guide for People with Stroke and their Families* is valuable to stroke patients and family members, as well as to health professionals, and to explore their comments and suggestions. Further aims are to identify: -

1. The self-reported effect reading the book has on stroke patients and their family,
2. The type of information that health professionals, patients, and family report as helpful,
3. The learning needs reported by the study patients and families as not met using the book,
4. The overall rating of the book,
5. The participation of health professionals in the delivery of the health information book,
and
6. The resource needs reported by health professionals who are required to distribute the book.

Chapter 2 Literature Review

A literature review was carried out using the Internet, library databases, and bibliographies of literature obtained from the original searches. The literature review was done to:

- * Examine the evidence of research into the effectiveness of a health information book.
- * Consider the determinants of a health information book.
- * Consider the stages of the health information development process.
- * Highlight examples of what should be considered for inclusion in the health information book for stroke patients' families.

The United States of America (US) was the pioneer in the provision of health information to patients (Shepperd, Charnock, & Gann, 1999). Similar efforts have been taken in countries like in the United Kingdom (UK), Canada, Australia and New Zealand (Du, Ma, & Li, 2016). Provision of high-quality and tailored information can let patients take more control of their health and allow them respond to health problems more quickly and better (Heinmann et al., 2015) and they may feel in more control (Husson, Mols, & Van De Pol-Franse, 2011). Patients may also have more positive attitudes towards their disease and, therefore, fully participate in health care and life decision making (Du, Ma, & Li, 2016). Patients' anxiety, distress, and dissatisfaction may increase if there is inadequate information which can depressingly affect the quality of life and the decision making power of patients (Mossman, Boudioni, & Slevin, 1999).

This brief literature review looks at seven previous studies that investigate the evaluation of health information booklets: two in Australia, one in the Netherlands, one in New York (US), one produced in New Zealand, and another two in the UK (Eames, Hoffmann, Worrall and Read, 2011; Hoffmann and McKenna, 2006; Wachters-Kaufmann, Schuling, The, & Meyboom-de Jong, 2005; Paul, Hendry, & Cabrelli, 2004; Leathem, Cupples, Byrne M. E., Byrne M.C., Smith, & Murphy, 2009; Parrinello, 1984; and Roy, Gasqoine, Caldwell, & Nash, 2015). These studies looked at the preferred delivery style and format of health information, reading ability of patients and their family members, content and design of written information, actual and desired provision of information, value of providing the written information to patients and family members, and the inclusion of patients and family members in the development and evaluation of the written information. This review will discuss their findings, limitations, and recommendations and is the basis for conducting the current research project. It will also highlight other studies that have evaluated other disease information booklets to provide a context for the present studies.

All of the above research was undertaken for the following reasons: to develop an evidence-based information book for patients and relatives, to identify how patients and relatives are finding the value of the book, to determine how patients' opinions could be helpful in designing an information book, and also to recognise the family's value with regards to outcomes.

A study was conducted by Eames, Hoffmann, Worrall, and Read in 2011 in a metropolitan hospital in an acute stroke unit in Brisbane, Australia, to identify the preferences of patients with stroke and their carers in terms of the format and delivery style of different categories of stroke information. The participants in the study were patients admitted to an acute stroke unit in Brisbane or the carer of the patients with the stroke. Participants were selected if they had

adequate English, cognition, communication, vision, and hearing to provide consent and to complete the survey, and who were living within 50 km of the hospital. Carers were still invited to complete the survey even if the patient was not eligible. Patients with aphasia were also invited to participate and aphasia friendly principles such as prompt sheets, gestures, and repeating of information were used. Data collection was done through face to face interview with a semi-structured questionnaire with a multiple response option and data were analysed using Statistics Software Package for Statistical Analysis (SPSS). Questions were asked prior to discharge with 34 stroke unit patients and 18 carers and at follow-up 3 months after discharge. There were 27 patients and 16 carers involved. In this study, researcher found that the preferred delivery style is a mix of active and passive styles and face to face, with written and telephone the preferred format for both patient and carers. It was also found that providing written material is vital before discharge and few months post-discharge, for all desired topics but especially for information about service and benefits. This research is worthy because it has explored the optimal way of modifying the communication of information to people with stroke and their carers. This research has some limitations, for example, it was restricted to an acute stroke unit, and neither mixed age group participants nor health professionals were included as participants. The study was also a small size and it assessed only the one method of delivery and format of education materials.

Hoffmann and McKenna (2006) evaluated the reading ability of content and the design of written information for patients after stroke and their caregivers. They also gave recommendations to improve written stroke information. The study was conducted on patients admitted to stroke unit of a major metropolitan public hospital in Brisbane. Patients with aphasia and their carers were also included with the help of speech pathologist. Patients who were not

included in the study were patients' whose communication skills were not appropriate for an interview, impaired cognitive status, lived further than 50 km from the hospital, whose prognosis was poor, who died, who had a severe visual impairment, or who did not speak English. Data collection was done using face to face semi-structured interviews and clinical data were used from patients' medical charts. Written materials analysis was done in terms of the reading level using the Simple Measure of Gobbledgook (SMOG) readability formula (calculates the reading level of the materials, using long words, defined as words of three or more syllabuses in 30 sentences, 10 sentences from starting, 10 from the middle, and 10 from the end of written material). Content and design characteristics were assessed using instrument Suitability Assessment of Materials (SAM) and reading ability was measured using Rapid Estimate of Adult Literacy in Medicine (REALM). The REALM is a reading recognition test that measures the reader's ability to pronounce 66 commonly used medical and lay terms for body parts and illness (Murphy, Davis, Long, Jackson, & Decker, 1993). Scores ranged from 0-66 (2nd grade level education which is needed to understand) 0-18 (3rd grade level) 19-44 (4th to 6th grade level), 45-60 (7th to 8th grade level) and 61-66 (9th grade level or above). Data analysis was done using the SPSS version 11 computer program. The study found only 22.8% patients and 41.7% carers received written information and the mean reading level of written information and mean reading level of written information was 11th grade. The patients' REALM was 7th to 8th grade level, the carers' REALM was 9th grade or higher. Most written materials (89%) scored only adequate in design and content as a written educational tool. This study is worthy because it highlighted that health professionals should keep in mind that when developing written materials reading ability and the information needs of patients' and carers'

reading level should be considered. The study has limitations: small sample size, and the participants recruited from one place.

Wachters-Kaufmann, Schuling, The, and Meyboom-de Jong (2005) had conducted a study to investigate actual information and what was the desired information after a stroke. The study was conducted in the north of the Netherlands, in the stroke unit of the university hospital of Groningen. The participants were stroke patients and their caregivers and a copy of the information guide was given three months after suffering from a stroke and final measurement was done at 12 months. A telephone survey method was used with a trained interviewer. Most of the questions were closed and a few were open ended. A total of 33 patients and 27 caregivers (wife, husband, partner, or daughter) participated in the research. The study found that the desired information providers were the GP, the physiotherapist and the neurologist. The patients' and caregivers' preference was to receive information within 24 hours and they wanted to be informed about, and be provided with, relevant written information. This research finding is important because it has addressed different concerns of patients and caregivers, regarding the provision of information, provision which could be considered in future to create written information and the provision of both verbal and written information. This study also had limitations, such as it recruited young male patients, who have few disabilities and few co-morbidities, and also had healthy caregivers. Patients who were admitted from a nursing home, patients with aphasia, or other cognitive impairment, were excluded.

Paul, Hendry, and Cabrelli (2004) did a study to find patient and relatives' needs while transferring from an intensive care unit (ICU). The study was conducted in the Tayside University Hospital, Scotland, UK. It was conducted in three phases. In the first phase, the information needs of patients and relatives at the time of transfer were identified. In second

phase an information book was designed, and in third stage book was introduced and evaluated. Semi-structured questionnaires were used to collect data and the convenience sampling method was used to recruit participants. In first stage seven patients and two relatives identified the information needs. For the second stage, the draft of an information book was designed using the information from the first stage (and different guidelines) and then this was reviewed by members of an MDT team (n=15) patients (n=4) and their relatives (n=3). The content of the book was focused on the transfer from ICU and recovery from illness. In phase three the book was introduced in consultation with ICU staff about book and appropriateness for certain patients and family members, and was distributed at least 24 hours before transfer. Twenty-five patients or relatives were given the book. Among them nineteen got this book in ICU and 6 received it in the ward within 24-48 hours after transfer. Of the 25 participants 18 were interviewed to evaluate the booklet. The research demonstrated the value of providing patients and relatives with written information about the transfer from ICU. In addition, the study has also confirmed the viability and importance of including patients and relatives in the process of booklet development to ensure that the information needs of the patients and relatives are being met. Researchers were also able to get helpful responses and comments to improve the booklet from the participating patients and relatives in their study, such as when is the appropriate time to receive the booklet. The information booklet focused on day to day activities rather than long-term goals. Some of the patients said the notes pages at the back were useful to write improvements they have made. The researchers, however, had assumed that patients who were interviewed at Phase 1 and Phase 3 of their study were literate, thus indicating that the readability level of the booklet was likely to have been appropriate. Similarly, the visual ability was not assessed and all respondents were European and spoke fluent English.

In Northern Ireland, Leathem et al., (2009) conducted qualitative research which had two phases, one before and another after the pilot of a randomised control trial of an information booklet that was provided to coronary heart disease patients at GP practices in four sites. The information book was provided in consultation with practitioners whose role was to encourage and support healthy lifestyle behaviours and medications' adherence. Focus group discussion was done using maximum variation sampling using exploratory questions and analysis was done using the computer software program NUDIST. The research found that utilising the opinions of a patient adds value when developing appropriate teaching materials. For example, in the evaluation, a draft of the booklet developed in the first phase (without patient input) the researcher was able to find participant opinion that the book had not included information about stress management, medication, and local community support maintaining a healthy lifestyle. The book was revised into A5 size format, using the views from the focus group participants. Participants found the book was useful especially in explanation of the relationship between lifestyle and heart disease. Patients were also happy with information regarding stress management and community support. The practical implications of the research are that by providing clear information to patients, this can help them with appropriate self-care management decisions and actions. It also supports structures and facilities available within their society. This recognises that the patients have a part to play in the information developed for them, and it also reveals consideration of their individual agenda. But, the focus groups were not used to obtain information in this research due to difficulty in assembling them. The researchers recommended quantitative measures could be used to evaluate the book.

The aim of a patient information resource is to provide health information to the patients and their family members to support and supplement verbal communication (New Zealand Ministry

of Health, 2012; NHS, Shetland, 2010). According to NHS, Shetland (2010) stated that “Patient information can take various forms including leaflets, booklets and factsheets, posters, videos, and DVDs, audiocassettes, websites, training aids, CD-ROMs and PDF files”.

The importance of good patient information is that it can remind patients and their carers about what they were told by health professionals. It also helps to ensure patients arrive on time with proper preparation for diagnostic tests and treatment. In the same way, it also involves patients and their carers in their treatment and their condition. Similarly, it also helps patients and carers to make informed decisions because it clearly outlines the risks, benefits, and possible side-effects of treatment. Patient information also outlines what to expect on the patient’s journey (NHS Shetland, 2010). Health professionals are legally and ethically liable in their practice while providing appropriate information to patients and because of this the standard of the information leaflet is important (Rajasundaram, Phillips, & Clay, 2006). NHS Shetland (2010) also states:

We need to assure that our written information contains a consistently high standard of information for our patient which is accessible, clear, and easy to understand. It should project a professional image and be instantly recognisable information is presented reflects on the board and creates a first impression.

Lindsay et al., (2008) recommended four things in Canadian best practice for stroke care. They are: -

Educational content should be specific to the phase of care or recovery across the continuum of stroke care and appropriate to patient, family and caregiver readiness and needs

The scope of the educational content should cover all aspects of care and recovery, including the nature of stroke and its manifestations, signs and symptoms; impairments and their impact and management, including caregiver training; risk factors; post-stroke depression; cognitive impairment, discharge planning and decision making; community resources, services, and support programmes; and environmental adaptations and benefits.

Education should be interactive, timely, up to date, provided in a variety of languages and formats (written, oral, aphasia friendly, group counselling approach), and specific to patient, family and caregiver needs and impairments. The provision of education should ensure communicative accessibility for stroke survivors.

Clinicians and/or teams should develop processes for routine patient, caregiver and family education in which designated team members are responsible for provision and documentation of education.

According to the New Zealand Ministry of Health (2012), several factors can affect the quality of a booklet. They are wording, sentences, the length of the information, design (including look, feel, colour, images, size, text style), and easy access to the resource.

Other patient information booklets' value has been observed by conducting a descriptive survey to ascertain the opinions of patients in the University of Rochester, Medical Centre, Rochester, New York, US. One of them is *Evaluation of a teaching booklet for arterial bypass surgery* Parrinello (1984). Parrinello (1984) developed the 19 page arterial bypass surgery patient booklet by consulting three vascular surgeons and then book was distributed by the nurses working in vascular surgery unit. Four page questionnaires were developed which contained demographic data, patients' previous experience of surgery, about the given information book,

and its effect on their surgical experience. The researcher was able to find several implications from this study. Firstly, patients scheduled for the same procedure have been found to have different learning needs. Secondly, no one can assume that a booklet alone can provide comprehensive teaching to the patients. Thirdly, nurses must assess the patients reading ability before providing a booklet. As a whole, this study helped to find patients' responses to a specific teaching booklet. However, the research was conducted by only one researcher so there is a chance of an experimenter bias because these kind of bias are prevalent if the single researcher is responsible in generating the hypothesis, collecting the data, and analysing the data (Marczyk, DeMatteo, and Festinger, 2005)

The current research will also get the opinions of the patients and family members about the usefulness of the information booklet *Life after Stroke: a Guide for People with Stroke and their Families*, which can provide several implications for their understanding of information about stroke.

Roy, Gasqoine, Caldwell, & Nash (2015) conducted a mixed method descriptive survey with purposive sampling to identify the education and information needs of families of patients with stroke in Auckland, New Zealand. Families were invited by placing flyers in clinical areas in the local hospital (where post-stroke assessment and rehabilitation services are provided) and the Stroke Foundation support groups. Health professionals, who were working currently with patients with stroke either in a hospital or in the community, were invited. Nineteen family members and 23 health professionals participated. Questionnaires used in the survey had both closed and open ended and two sets of questionnaires were used, one for family, and another for health professionals. Questions were available in both electronic and postal versions. Data analysis was done using SPSS and thematic analysis. The researcher recommended that to

ameliorate the gap between actual practice and best practice there is a need for reflection on, and evaluation of, current education provision. There is also a need to reassess how best health personnel can deliver quality education that meets the needs of the stroke survivors and their family members. To provide optimum practice to the stroke survivors and their family, post-stroke education should be based on the assessment of changing needs and health literacy across the post-stroke field. According to Roy et al. (2015):

Access to appropriate information post-stroke was problematic for most families in both quality and timeliness and was compounded by the nature of the experience shock, following the sudden onset and adjusting to change family dynamics. Information needs specific to stroke families are often overloaded. It is important to communicate effectively with families and acknowledge that they may have complex needs that are different to the stroke survivors needs.

Although, Roy et al. (2015) were able to describe the perceptions of health professionals and family members regarding post-stroke information there is a limitation in that this study has excluded the stroke survivors and there was limited ethnic diversity, that is, of the 19 family members 18 were New Zealand European.

My research project surveys the opinions of MDT members, patients and family members about *Life after Stroke: a Guide for People with Stroke and their Families* in a stroke rehabilitation ward (Ward 2A) of The Princess Margaret Hospital (later moved to Burwood Hospital Ward DG) Christchurch. The purpose is to obtain feedback about the book and see how well the book is able to provide information to patients and their family members. It investigates whether the book is able to bring changes in the feelings and coping mechanisms for patients and family

members. The study also addresses some of the limitations of previous research. Stroke survivors were included and the research tried to include different ethnic groups as well. This research explored whether the health professionals are distributing the book or not. If not, why they are not distributing it, and if they have any suggestions for the book.

Chapter 3 Methods

A cross-sectional survey with a semi-structured questionnaire was used to ascertain responses from stroke patients, their family members, and health professionals to determine the value of the information book *Life after Stroke: a Guide for People with Stroke and their Families*. The survey asked different questions to see how the patients and their family members finding the book in regard to ease of reading and understanding, accessibility, usefulness, and value. Two sets of questionnaire were developed: one for health professionals another for patient and family members. The questionnaires contained both closed and open ended questions. A literature review was done prior to making the questionnaire so that this research could address elements missing from earlier research and include important elements recommended in the literature. The semi-structured questionnaires were developed because they address the main themes and allow some flexibility in the respondent's answers to develop issues and themes that arise (MacDonald and Headlam, 2008). The validity of questions were maintained to avoid bias arising from asking wrong questions. Face validity of questions were maintained by conducting a pilot study, asking non-experts to rate the questions and asking whether they have any difficulties with understanding the questions. Some feedback came from them which was used to amend the questionnaire. For content validity the questionnaire was sent to experts (supervisor, co-supervisors, the Nursing Director of CDHB, the Charge Nurse of Ward 2A/DG, and the Stroke Foundation) and their feedback was incorporated in the final version of the questionnaire.

In research, ethics plays a major role, and therefore ethical approval was sought from the University of Canterbury Human Ethics Committee (UC HEC), the Canterbury District Health Board (CDHB: the local health authority), and the Māori Research Advisory Group of both UC

HEC and CDHB, and the Stroke Foundation of New Zealand, prior to data collection. Approval was obtained from all the organisations and letters of approval are presented in Appendix E. Participation was voluntary and respondents were free to decline the survey. Respondents' answers and, their personal details were treated as confidential.

Stroke patients in the research refers to the patients who have been admitted to the stroke rehabilitation ward to rehabilitate after being diagnosed with a stroke. *Family members* refers to husband, wife, partner (de facto relationship), son, daughter, in-laws, and grandchildren. *Health professional* refers to all MDT members who work on the stroke rehabilitation ward in The Princess Margaret Hospital or Burwood Hospital and includes, doctors, nurses, physiotherapists, social workers, occupational therapists, speech-language therapists, and dietitians. Health professionals only participated if they were happy to do so.

This study involved a cross-sectional quantitative survey because according to WHO (2001) cross-sectional survey entails the data collection of data on as in term implies, a “cross-section of the population which may comprise the whole population or a proportion (sample) of it”. Cross-sectional studies also provide a wealth of data and are less costly than perspective studies (WHO, 2001).

A quantitative method of data collection based on a cross-sectional survey with simple semi-structured questions was used.

Target population

In Ward 2A of The Princess Margaret Hospital, there were 20 beds and later this ward was moved to Burwood Hospital where there were 21 beds in Ward DG. The target population were the MDT

members, stroke patients who can read and write in English and who are able to complete reading the book, and family members of stroke patients in this ward who can read and write in English. The patient information file was used to determine if patient had the cognitive and language skills to participate fully. An assessment was also done at the time of completing the information sheet. Patients who can read and understand and verbalise but cannot write were also included by the researcher administering the questionnaire on their behalf.

The sample size was determined using the formula $n = z^2 (1-P)/d^2$, where the level of confidence (Z), expected prevalence (P), and precision (d) were inputted into the formula. The conventional level of confidence (Z=1.96) was chosen to present results with a 95% Confidence Interval (CI). The estimation of the prevalence rate of the survey response is unknown and so 0.5 was used for the calculation as a conservative estimate. To obtain a narrow confidence interval (good precision), (d) was decided as 0.10. The estimation of sample size will be 96.04. If we expect a refusal rate of 25% then approximately 128 people will need to be asked to obtain the final sample of 96 people.

The purpose was to find out the proportion of respondents who read the book: *Life after Stroke: a Guide for People with Stroke and their Families*. It took five months to collect the data. A convenience sample selection process was used, because time and resource constraints did not permit a random sample selection process.

The questionnaire was handed out to the Older Person's Specialist Health Services Nurse in-charge and ward in-charge Nurse. All the staff in the Ward 2A/DG were informed about the research and the research study was discussed in a meeting. The study was advertised in Ward 2A/DG. This was to ensure the health managers and staff were aware of the study. The questionnaire was also hand delivered to participants by the researcher after written approval was gained from the Older

Person's Specialist Health Services. The researcher was present during visiting hours 5 days a week to collect data from the family members. Respondents had a right to refuse to participate in the research. If the patient's family members took away the questionnaire from Ward 2A/DG, they were asked to bring the completed questionnaire back with them the next time they visited the patient and to hand the questionnaire to the Nurse-in-charge of the ward for that duty, who put the questionnaire in the researcher's lockable cabinet, or respondents could post it back to hospital, in envelopes that were provided. The target sample size was 384 including MDT members, patients, and family members. Based on this sample size 384 questionnaires were printed out.

The questionnaire used questions that were formulated with respect to the study purpose. The participants were asked to select a single answer or indicate their preference that best represents their situation and understanding, and for some questions, participants were requested to write their views in the spaces provided. The questionnaire format required the participant to tick a response option box (or boxes) that best represents their situation. Data were collected and safely stored in a sealed envelope and brought back to the University of Canterbury where it was stored in a locked cabinet. There were not any incentives for participating in research and respondents were not required to write their name because the questionnaires were anonymous.

Research design and Procedures

The pilot study was completed prior to the real study and the questions were modified as necessary. After that participants were notified verbally prior to distribution of the questionnaire. The study data collection was undertaken in from June 2016 to October 2016. It took between 15 to 30 minutes of the respondent's time to complete the questionnaire. Each participant was asked to provide informed consent to participate in the research.

A cross-sectional descriptive survey design was used, similar to that described by Roy et.al. (2015) with the aim to ascertain the value of the *Life after Stroke: a Guide for People with Stroke and their Families*. Two questionnaires were developed: one for health professionals and another for patients and family members. The questionnaires covered topics on demographic information, a rating of the book and its contents, and suggestions for a future review of the book.

Seventy-five individuals participated in the research: 31 participants were health professionals and 44 were either patients, family members, or caregivers. There were 68 variables assessed by the questionnaire for patient and family members, and 34 variables in the questionnaire for health professionals. Variables consisted of collected variables and constructed variables for the analysis.

Data analysis was undertaken separately for the two set of questionnaires, focusing on 4 main topics using SPSS version 24 computer software. To minimise bias and to get accurate result data screening was done to make data complete and accurate prior to data analysis. After that the database was constructed by considering all the variables and developing data codebook. According to Marczyk, DeMatteo, and Festinger (2005) “a data codebook is a written or computerized list that provides a clear and comprehensive description of the variables that will be included in the database”. If the data codebook is not defined well database may be useless (Marczyk, DeMatteo, & Festinger, 2005). After that data entry was done and to find missing data and incorrect formatting frequency of each variable was run.

3.1 Questionnaire for patients and family members

3.1.1 A profile of 44 participants

Demographic data was analysed for patients and family member participants which included: participants I.D., gender, age, ethnicity, religion and level of education. Frequency tables and graphs were constructed to illustrate the results in Chapter 4.1.1.

3.1.2 Accessibility of information book *Life after Stroke: a Guide for People with Stroke and their Families*

An analysis of accessibility was derived from responses to questions about whether the book is given or not, if yes who gave it, where was it given, which book was given, do they know that this book is available in electronic form as well and what format type of resources do they like to read? These results are presented in Chapter 4.1.2.

3.1.3 Overall evaluation of the book

These responses relate to questions about how patients and family members feel about the book. Is it easy to understand or not? What is their opinion about the book, how did they feel after reading it and how useful was each section? These results are presented in Chapter 4.1.3.

3.1.4 Comments and suggestion

In this section, all the comments and suggestions provided by patients and family are described.

3.2 Questions for health professionals

3.2.1 A profile of 31 health professionals

Demographic data were collected for all staff members, for example their position, type of the employment, working history, and their age. These results are presented in Chapter 4.2.1 as bar graphs.

3.2.2 Knowledge about the book

This section presents whether staff are aware of the book or not, whether they are aware that the book can be found in electronic form, and whether they have read it or not. These results are presented in Chapter 4.2.2.

3.2.3 Distribution of book

This section presents which information resources (CDHB resources or the *Life after Stroke* book) staff members prefer to distribute and when? If they are not distributing resources or the book, what is the reason behind that? The relationship (if any) between the distribution of the book and length of employment is explored. These results are presented in Chapter 4.2.3.

3.2.4 Evaluation of the book

This section presents what the health professional thinks about the book, and how it is written, and how highly they are rate it. These results are presented in Chapter 4.2.4.

3.2.5 Comments and suggestions

In this section, all the comments and suggestions provided by health professionals are described. This is presented in Chapter 4.2.5.

3.3 Results of some common variables which are assessed with patients and family member and the staff

Finally, the findings of patients, family members, and staff are merged to generate an overall evaluation of the book, plus comments and suggestions.

Chapter 4 Results

A total of seventy-five participants participated in the research, 44 patients and family members and 31 health professionals. One hundred and seven staff worked in Ward 2A/DG. This includes all regular staff, casual staff, and agency staff. During the data collection period from June to October 2016, there were 90 stroke patients in the ward. Of them, thirty patients met the criteria to participate in research but only 19 patients participated in research and rest of them were not interested in participating. This gives a patient response rate of 21%. Of these 19 patients, three took the questionnaire home, filled it in, and sent it back to the hospital for the researcher to collect. The questionnaire of patients and family members comprised 68 variables and the health professional questionnaire had 34 variables.

The SPSS data set was established for the purpose of analysis of results. The results are discussed below.

4.1 Questionnaire for patients and family members

4.1.1 A profile of 44 participants

Of the 44 participants in this questionnaire, 19 participants were patients; 19 participants were family members, and 4 participants were both family members and a caregiver of the patients and 2 were caregiver only. The ages and gender of the patients and family members are presented in Figure 1. Interestingly, there were more female participants in the questionnaire for patients and family members in most of the age groups. In total 61.4% females participated whereas only 38.6% were male participants. Of the 19 patients, 10 were female and 9 were male. Of 10 family members, 10 were over 65 years, 2 family members were in age between 55-64 years, 4 were between 45-54 years, and 3 were below 45 years. In the age group over 65 years, 10 participants were family members, 2 respondents were caregivers and 3 were family members who were also a caregiver.

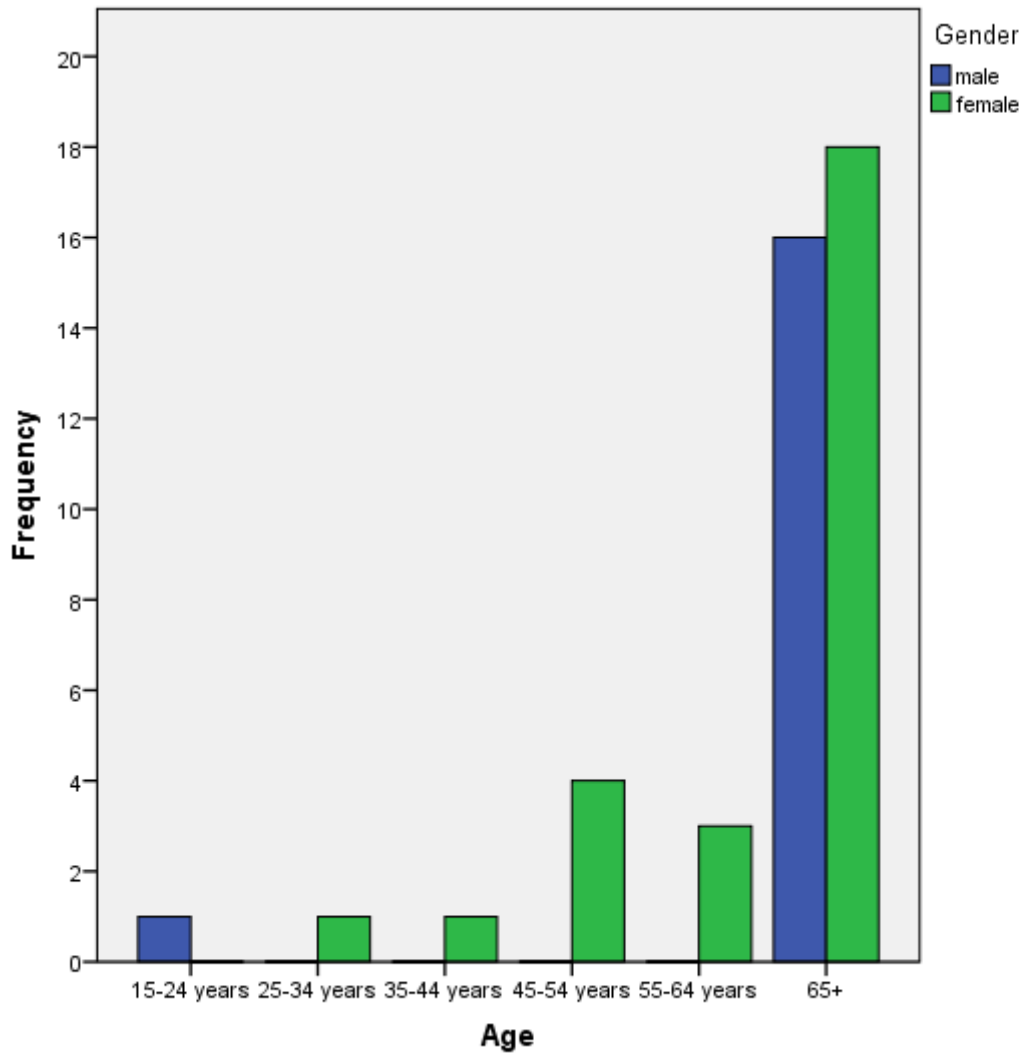


Figure 1: The age and gender of patients and family members who participated in the research.

The majority of participants (93%) were New Zealand European.

As shown in Figure 2 the largest proportion of participants, who reported a religious affiliation (n= 36) are Christian Anglican (41.7% (15/36)) followed by Christian Presbyterian (7.8%).

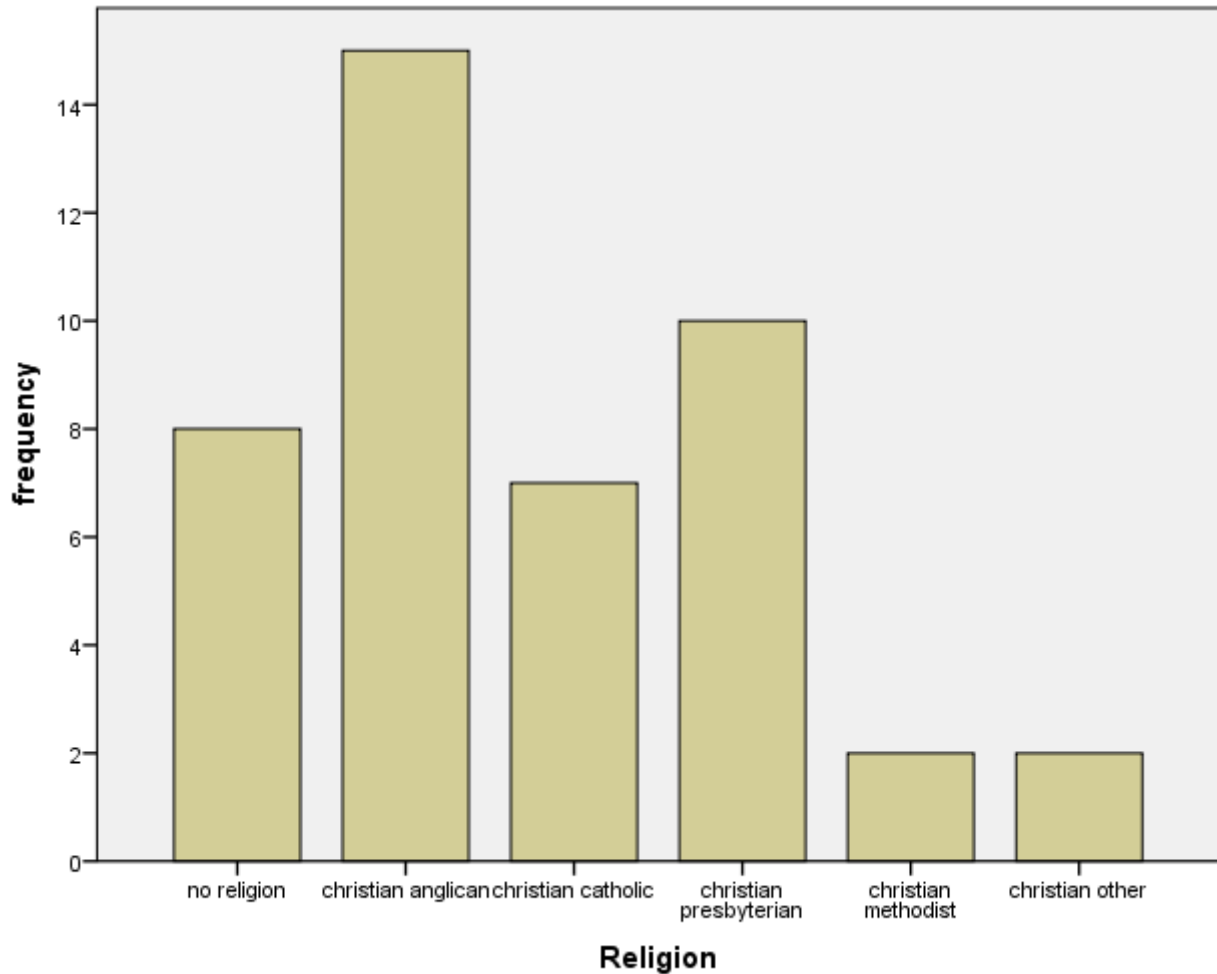


Figure 2: Reported religion of patients/family members

In terms of educational level, the largest proportion of respondents (22.7%) of the 44 participants had completed a university degree. On the other hand, 20.5% of participants had no qualification. Just under 16% of participants had completed high school certificate, 9.1% had a polytechnic qualification, and the remainder had either Sixth Form Certificate, University Entrance, or Higher School Certificate. The educational level obtained is presented in Table 2.

Table 2 The educational qualification of patient/family members who participated in the survey.

| Count | | Id | | | | Total |
|---------------|---------------------------|---------|---------------|-----------|-----------------------------|-------|
| | | patient | family member | caregiver | family member and caregiver | |
| Qualification | none | 4 | 3 | 1 | 1 | 9 |
| | school certificate | 6 | 1 | 0 | 0 | 7 |
| | sixth form certificate | 1 | 1 | 0 | 0 | 2 |
| | university entrance | 0 | 0 | 0 | 2 | 2 |
| | high school certificate | 1 | 1 | 0 | 0 | 2 |
| | polytechnic qualification | 1 | 2 | 0 | 1 | 4 |
| | university degree/diploma | 3 | 7 | 0 | 0 | 10 |
| | other | 3 | 4 | 1 | 0 | 8 |
| Total | | 19 | 19 | 2 | 4 | 44 |

It is revealed in Table 2 among 19 patients, the largest number of patients (n=6) had School Certificate followed by (n=4) no qualification and 3 patients had University Degree/Diploma. In contrast, among 19 family members the largest number (n=7) had University Degree followed by (n=4) participants who reported other qualifications and 3 family members reported they do not have a qualification.

4.1.2 Accessibility of the information book *Life after Stroke: a Guide for People with Stroke and their Families*

Most participants (59.1%) received a stroke information book.

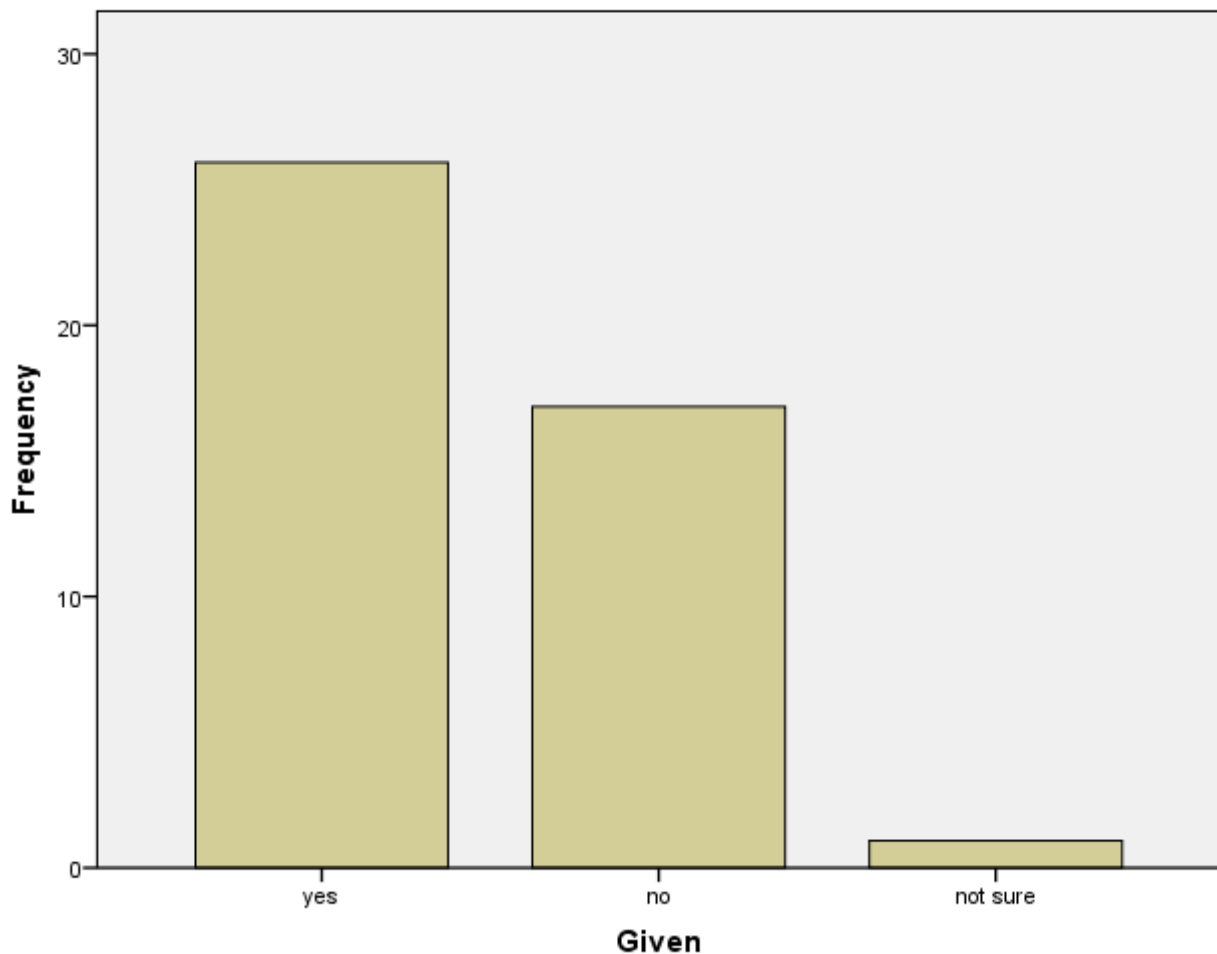


Figure 3: Participants who were given the stroke information book.

The survey responses show that largest proportion (42.3%) participants were given a book by nurses (both Registered Nurses (RN) and Enrolled Nurses (EN) because, most of the patients and family members cannot identify the level of nurses. Person who comes in sky blue uniform to do medication and provide nursing care is nurse for them), followed by 26.9% of participants saying that they received an information book from a social worker. Interestingly, among the 26 participants who received a book about stroke, (n=23) participants were given the *Life after Stroke: a Guide for People with Stroke and their Families*. The study also showed that 65.4% of

participants received stroke information book in the stroke rehabilitation ward (Ward 2A/DG), but some also received the book in other locations.

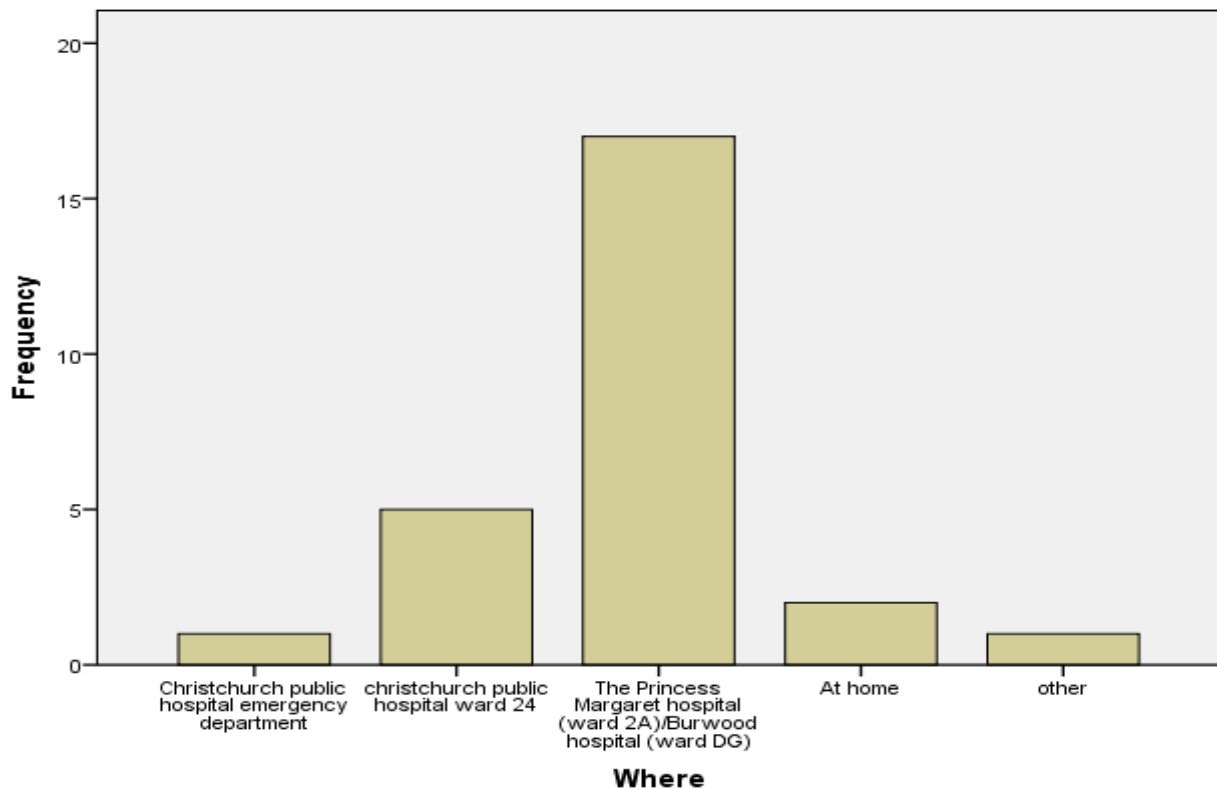


Figure 4: Place where participants received stroke information book

From the survey responses, it was found that the majority (73.08%) of participants were unaware of the electronic form of *Life after Stroke: a Guide for People with Stroke and their Families*. The majority (96.2%) of participants prefer reading paper resources.

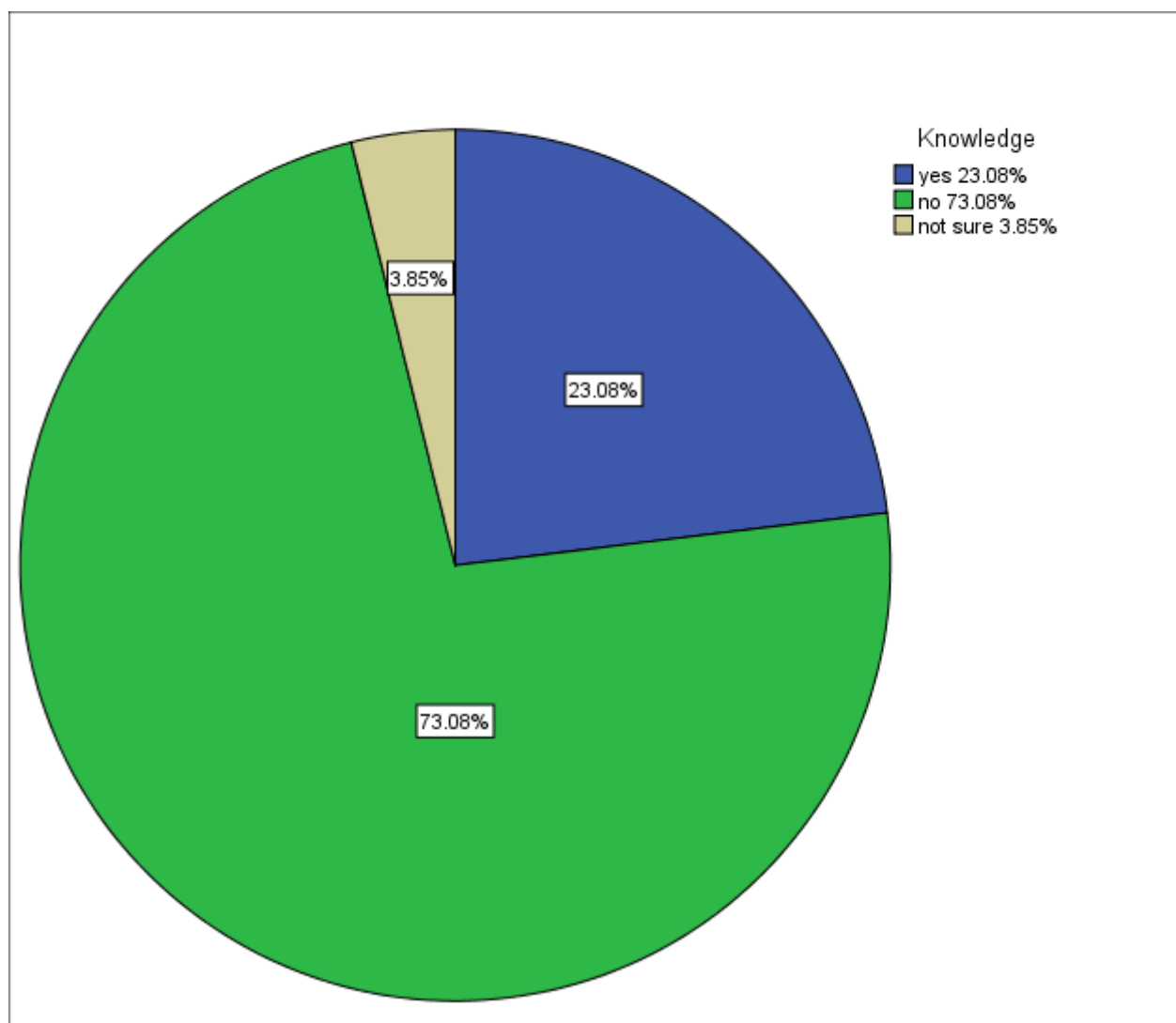


Figure 5: Knowledge about an electronic form of *Life after Stroke: a Guide for People with Stroke and their Families*

4.1.3 Overall evaluation of the *Life after Stroke* book

To provide an overall evaluation of the *Life after Stroke* book, questions in the survey were directed at determining the value and worth of the book. From the survey, it was found that the

majority (92.3%) of participants were happy with the written content of the book. From crosstabulation, it is also found that majority (92.3%) of patients found easy to understand. See Table 3.

Table 3 The number of participants who found the words in the book easy to understand.

| | | Words | | Total |
|-------|-----------------------------|-------|----|-------|
| | | yes | no | |
| I.D. | Patient | 14 | 0 | 14 |
| | Family member | 6 | 2 | 8 |
| | Caregiver | 2 | 0 | 2 |
| | Family member and caregiver | 2 | 0 | 2 |
| Total | | 24 | 2 | 26 |

Two of the family members said the book is too long and too complicated. The study showed that all the participants were happy with the font size. A majority (88.5%) of participants think that the book has about the right amount of information.

Interestingly, it was found from survey that 19 participants had a better understanding of their role in rehabilitation after reading the book *Life after Stroke: a Guide for People with Stroke and their Families*. The finding from the survey also indicated that many participants felt they were more knowledgeable about what is going to happen in rehabilitation and another 12 participants felt more confident about rehabilitation. One respondent, however, reported finding it hard to control their emotions after reading the book.

Table 4 The participant's evaluation of each section of the stroke information booklet

| Sections in the book | Very useful | Useful | not useful | Did not read | NA |
|---|---|--|-------------------------------|---------------------------------------|--------------------------------------|
| The first week (colour code green) ➤ Information on stroke | 14 (53.8%) | 11 (42.3%) | 0 | 1 (3.8%) | 0 |
| The effect of stroke (colour code pink) ➤ How damage to different parts of the brain affects different function? ➤ Day to day difficulties can result from stroke ➤ Practical recommendations for coping with functional problems caused by a stroke. | 16 (61.5%) 9 (34.6%) 7 (28.0%) | 9 (34.6%) 12 (46.2%) 11 (44.0%) | 0 0 1 (4.0%) | 1 (3.8) 2 (7.7%) 2 (8%) | 0 3 (11.5%) 4 (16%) |
| The rehabilitation experience (colour code orange) ➤ Introduction of the rehabilitation process ➤ Therapy | 11 (42.3%) | 13 (50.0%) | 1 (3.8%) 0 | 1 (3.8%) 1 | 0 0 |

| | | | | | |
|-------------------------------------|---------|---------|--------|--------|--------|
| | 15 | 10 | | (3.8%) | |
| ➤ Reaction to any loss after stroke | (57.7%) | (38.5%) | 0 | 1 | 0 |
| | 11 | 14 | | (3.8%) | |
| | (42.3%) | (53.8%) | | | |
| ➤ Stroke and the family/whānau | | | 1 | 1 | 2 |
| | 10 | 12 | (3.8%) | (3.8%) | (7.7%) |
| | (38.5%) | (46.2%) | | | |
| ➤ From hospital to home | | | 0 | 1 | 1 |
| | 8 | 16 | | (3.8%) | (3.8%) |
| ➤ Stress | (30.8%) | (61.5%) | 1 | 2 | 1 |
| | 9 | 13 | (3.8%) | (7.7%) | (3.8%) |
| | (34.6%) | (50%) | | | |
| ➤ Tiredness | | | 0 | 2 | 0 |
| | 11 | 13 | | (7.7%) | |
| ➤ Restlessness | (42.3%) | (50%) | 0 | 1 | 2 |
| | 8 | 15 | | (3.8%) | (7.7%) |
| | (30.8%) | (57.7%) | | | |
| ➤ Depression | | | 0 | 1 | 1 |
| | 12 | 12 | | (3.8%) | (3.8%) |
| | (46.2%) | (46.2%) | | | |
| ➤ Frustration | | | 0 | 1 | 1 |
| | 10 | 14 | | (3.8%) | (3.8%) |
| | (38.5%) | (53.8%) | | | |

| | | | | | |
|------------------------------------|---------------|---------------|-------------|-------------|---------------|
| ➤ Problem-solving | 6 (23.1%) | 18 (69.2%) | 0 | 1 (3.8%) | 1 (3.8%) |
| ➤ Relationship | 8 (30.8%) | 15 (57.7%) | 0 | 1 (3.8%) | 2 (7.7%) |
| ➤ Goals | 17 (65.4%) | 7 (26.9%) | 0 | 2 (7.7%) | 0 |
| ➤ Independence | 14 (53.8%) | 10 (38.5%) | 0 | 2 (7.7%) | 0 |
| ➤ Organising the day | 9 (34.6%) | 15 (57.7%) | 0 | 1 (3.8%) | 1 (3.8%) |
| ➤ Returning to work | 4 (15.4%) | 6 (23.1%) | 1 (3.8%) | 1 (3.8%) | 14 (53.8%) |
| ➤ Life after stroke for caregivers | 11 (42.3%) | 8 (30.8%) | 1 (3.8%) | 2 (7.7%) | 4 (15.4%) |
| ➤ Stroke in younger people | | | 1 | 1 | 15 (57.7%) |

| | | | | | |
|--|---------------|---------------|-------------|--------------|-------------|
| | 5 (19.2%) | 4 (15.4%) | (3.8%) | (3.8%) | |
| Facts and further experience (colour code blue) | | | | | |
| ➤ Driving after a stroke | 14 (53.8%) | 8 (30.8%) | 2 (7.7%) | 2 (7.7%) | 0 |
| ➤ Stroke clubs | 7 (26.9%) | 14 (53.8%) | 1 (3.8%) | 2 (7.7%) | 2 (7.7%) |
| ➤ Helping to prevent stroke | 15 (57.7%) | 9 (34.6%) | 0 | 1 (3.8%) | 1 (3.8%) |
| ➤ Eating for health | 14 (53.8%) | 11 (42.3%) | 0 | 1 (3.8%) | 0 |
| ➤ Assistance | 13 (50%) | 11 (42.3%) | 0 | 1 (3.8%) | 1 (3.8%) |
| ➤ Glossary | 11 (42.3%) | 10 (38.5%) | 0 | 5 (19.2%) | 0 |

Key: NA= Not Applicable

From the study, it was found that the majority (53.8%) of participants felt that the information on stroke in the first week section was very useful and 42.3% of participants felt it was useful. Only 3.8% of participants did not read this section of the booklet.

It was also found that in the effect of stroke section: *How damage to different parts of the brain affects different function*, was deemed very useful by 61.5% of participants and useful by 34.6% of participants, with only 3.8% of participants not reading this section. The section on *difficulties in the day to day life which can be caused by a stroke* was felt to be useful by (46.2%) of participants but 11.5% of participants felt it was not applicable to them and 7.7% of people did not read the section. In the same way, the largest proportion (44%) of respondents felt *the practical recommendations for coping with functional problems caused by a stroke* section were useful followed by 28% of respondents who felt it was very useful. Sixteen percent of participants felt the section was not applicable.

The survey also revealed how useful the *rehabilitation experience* section of the book was perceived to be. This section comprised several sub-sections. Half of the respondents felt the *introduction* to the rehabilitation process was useful and 42.3% of respondents felt it was very useful. More than half felt the *therapy* section was very useful and 38.5% participants felt that section was useful. Just over half of the participants deemed the section *Reaction to any loss after stroke* was useful and 42.3% of respondents felt this section was very useful. Likewise, nearly half the respondents felt section *Stroke and the family* was useful and 38.5% of respondents felt it was very useful. Nevertheless, 7.7% of respondents felt the section was not applicable. Six out ten of respondents felt the section *from hospital to home* was useful. Another section *stress* was felt useful by 50% of respondents and 34.6% respondents felt it was very useful. Another section *tiredness* was also felt useful by half of the respondents and

42.3% participants felt it was very useful. In the same way section *restlessness* was also felt useful by more than half of the respondents and 30.8% of respondents felt it was very helpful. Nearly half of participants felt the *depression* section was very useful and the same percentage participants thought it was useful as well. While looking at the *frustration* section in the book from the survey, it was found that more than half of the respondents found it was useful and 38.5% respondents found it was very useful. Surprisingly, nearly 70% of participants felt the *problem-solving* section was useful and only 23.1% of people felt it was very useful. Likewise, nearly 60% respondents felt the *relationship* section was useful. Interestingly, the section on *goals* was felt very useful by 65.4% of the participants while 26.9% of respondents felt it was useful. Nearly, 60% of participants felt the section on *independence* was very valuable. The majority (57.7%) of participants thought the section *organising the day* was useful and 34.6% of participants felt the section was very useful. In contrast, more than half of the respondents felt that the section *returning to work* was not applicable while 15.4% of people felt the section was very useful. The *life after stroke for caregivers* section was felt very useful by 42.3% while 15.4% of participants felt the section was not applicable. Nearly six out of the participants thought the *stroke in younger people* section is not applicable while only 19.2% of participants thought it was very useful.

The survey was also able to find how useful the section was on *Facts and further experience*. It also has six sub-sections. From the survey, it was found nearly half of respondents felt the section *driving* was very useful and more than half the participants felt the section *stroke club* was useful. The section *helping to prevent stroke* was felt to be very useful by 57.7% of participants and useful by 34.6% of participants. Similarly, the section *eating for health* was also felt very useful by a majority of participants (53.8%). In a similar way, half the

respondents found the section *assistance* was very useful. Of the *glossary* section, 19.2% of participants did not read it but 42.3% of participants felt this section is also very useful.

The survey also found that of the 26 participants who responded, 13 respondents were happy with the presentation of the information but (n=10) respondents were not. Of these 10 respondents who stated that information could be presented in other formats, most (n=7) said it could be presented by displaying the information on television screens in the hospitals and at GP practices and (n=5) reported that it could be displayed on television screens in other public places.

The study showed that 57.7% of the respondents were happy with the information in the book, but 11.5% of participants would also like to see additional information in it. The topic which the respondents were wanting to see as additional information was about having a *stroke club*, *double vision*, and *information about grants and the time frame for the financial assistance*.

From the study, it was also found that the majority (80.8%) rated the book was very useful.

4.1.4 Comments and suggestion

A number of participants made positive comments about the book.

One participant noted that

“the book is well covered and good for wide range of people”.

Another participant noted that

“it is organised with colour code, information is easy to read and helpful to both patients and caregivers”.

Other comments noted that:

“the book is also reinforcing knowledge as related to the condition participants are having”.

“It has strong encouragement throughout and it is also helping to prevent stroke”.

“happy with ring binding and lay out of the book”.

One participant suggested that:

“The shorter version maybe 2-3 pages could be given to all visitors and stroke patients, particularly early in the hospital stay”.

Another participant suggested that:

“It would be good if they could find about stroke clubs and their offer, information about grants and time frames for financial assistance”.

And (n=1) respondent said

“It would be good if there is a little bit more about double vision”.

4.2 Questions for the health professionals

4.2.1 A profile of 31 health professionals

A total 31 staff participated in the survey, the majority (58.1%) were Registered Nurses.

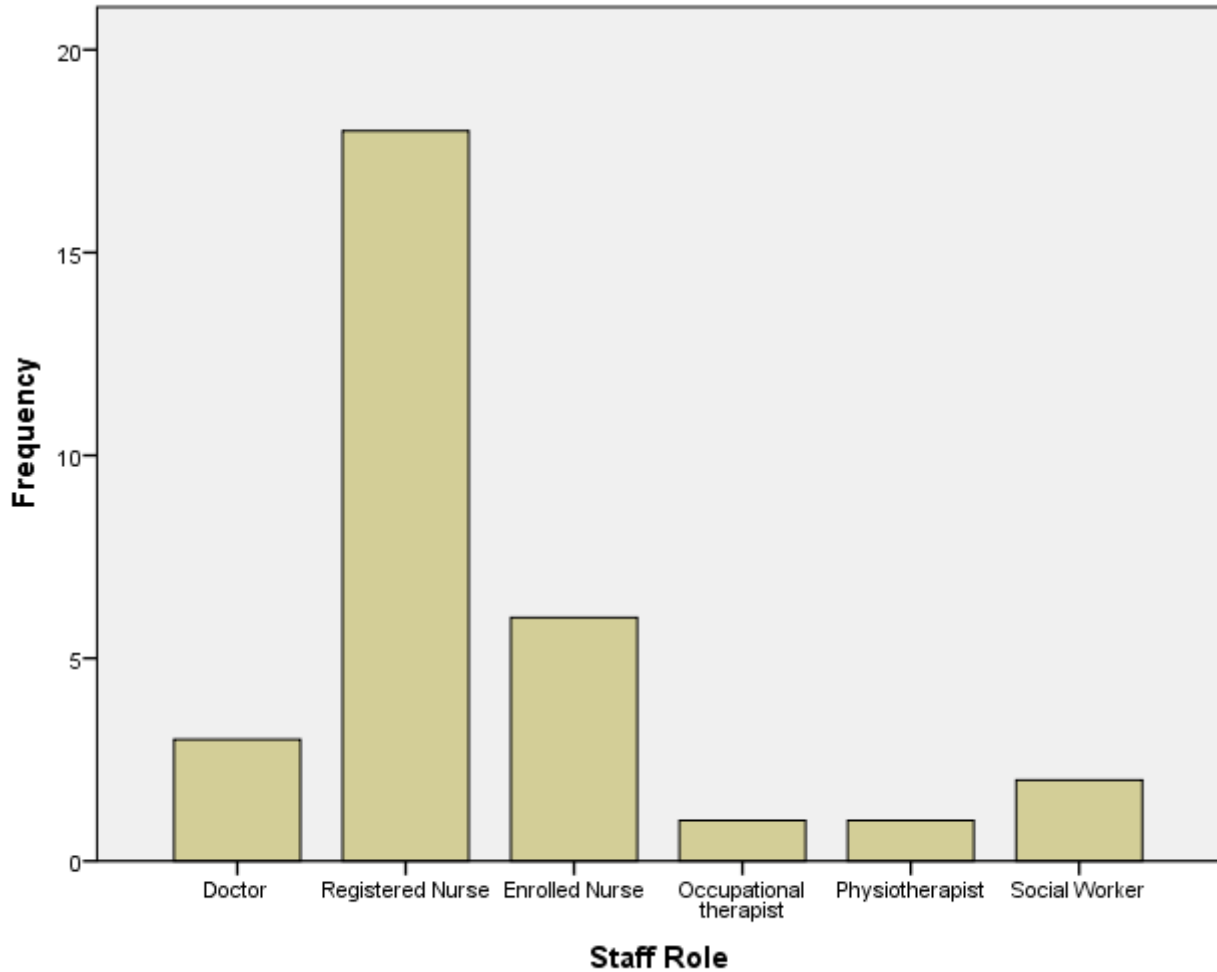


Figure 6: Staff members who participated in the research, by occupation

Of the health professional respondents, 12 were employed full-time, 11 respondents were casual staff, and 8 participants were part-time staff. Just over a quarter (25.8%) are between the ages of 25- 44 years and a small percentage (6.5%) is older than 65 years. The survey responses showed that nearly one third (32.3%) of respondents have worked for more than five years but over

quarter (25.8%) had worked in their health professional capacity for less than 6 months.

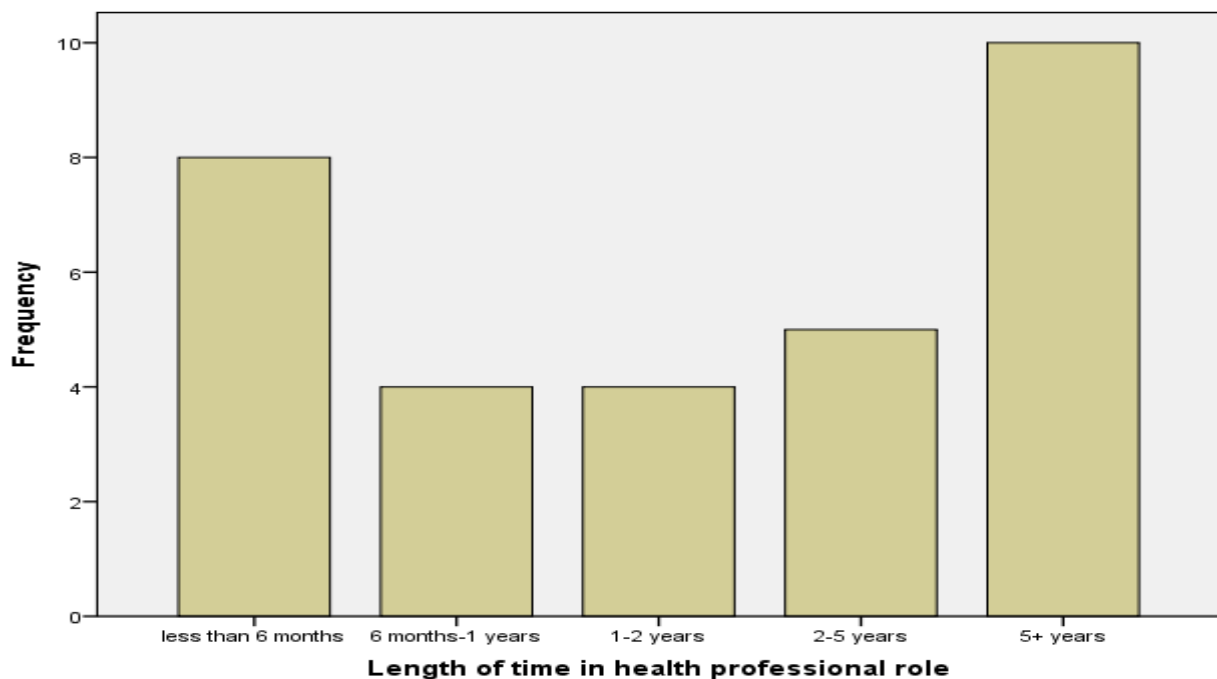


Figure 7: The reported length of time working in the stroke rehabilitation ward by staff members.

4.2.2 Knowledge about the book

A majority of the staff respondents (80.6%) have heard about the *Life after Stroke* book and just over three quarters (77.4%) of staff respondents have read the book. Interestingly, only 5

respondents reported knowing about the electronic form of the book.

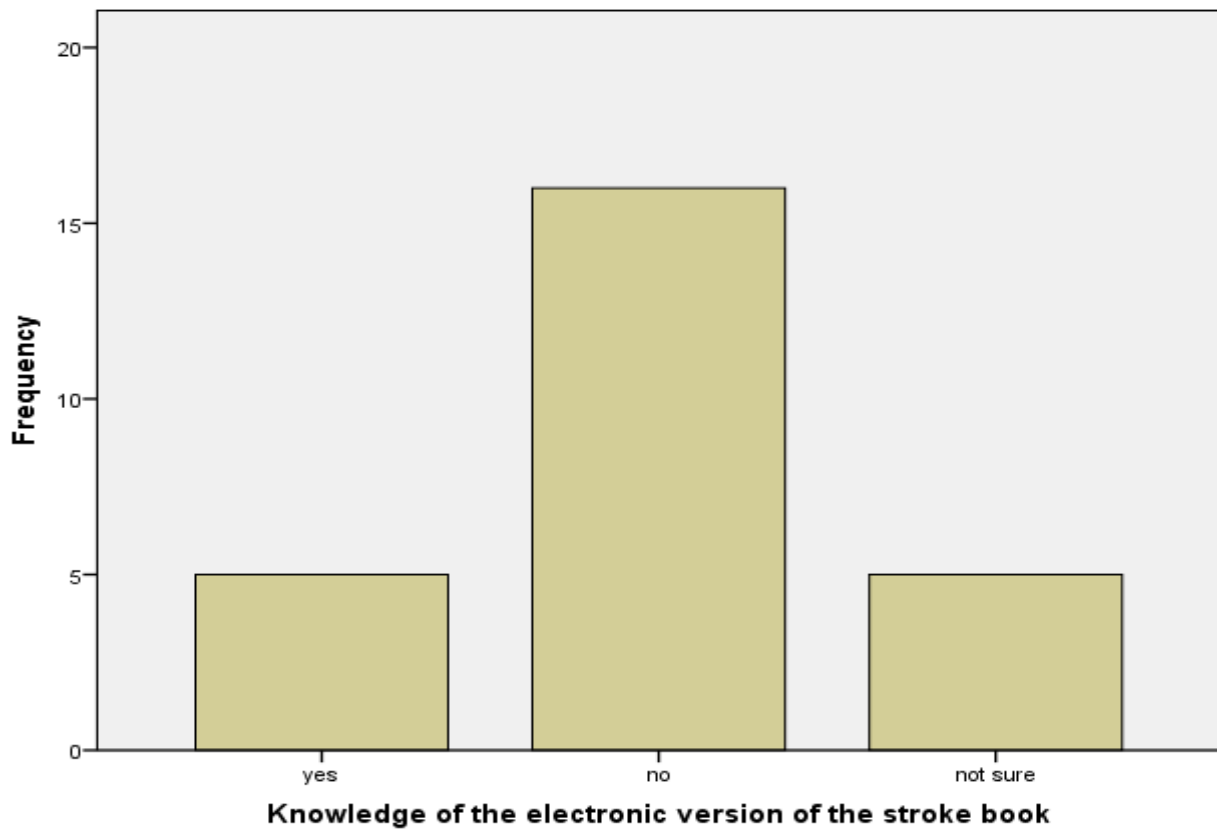


Figure 8: Reported knowledge about an electronic version of *Life after Stroke: a Guide for People with Stroke and their Families*

4.2.3 Distribution of the book

From the survey, it was found that nearly half of the health professionals prefer to distribute both the CDHB stroke information resources and the *Life after Stroke: a Guide for People with Stroke and their Families*. One respondent noted the CDHB resources can be too for ordinary patients and their family members to understand.

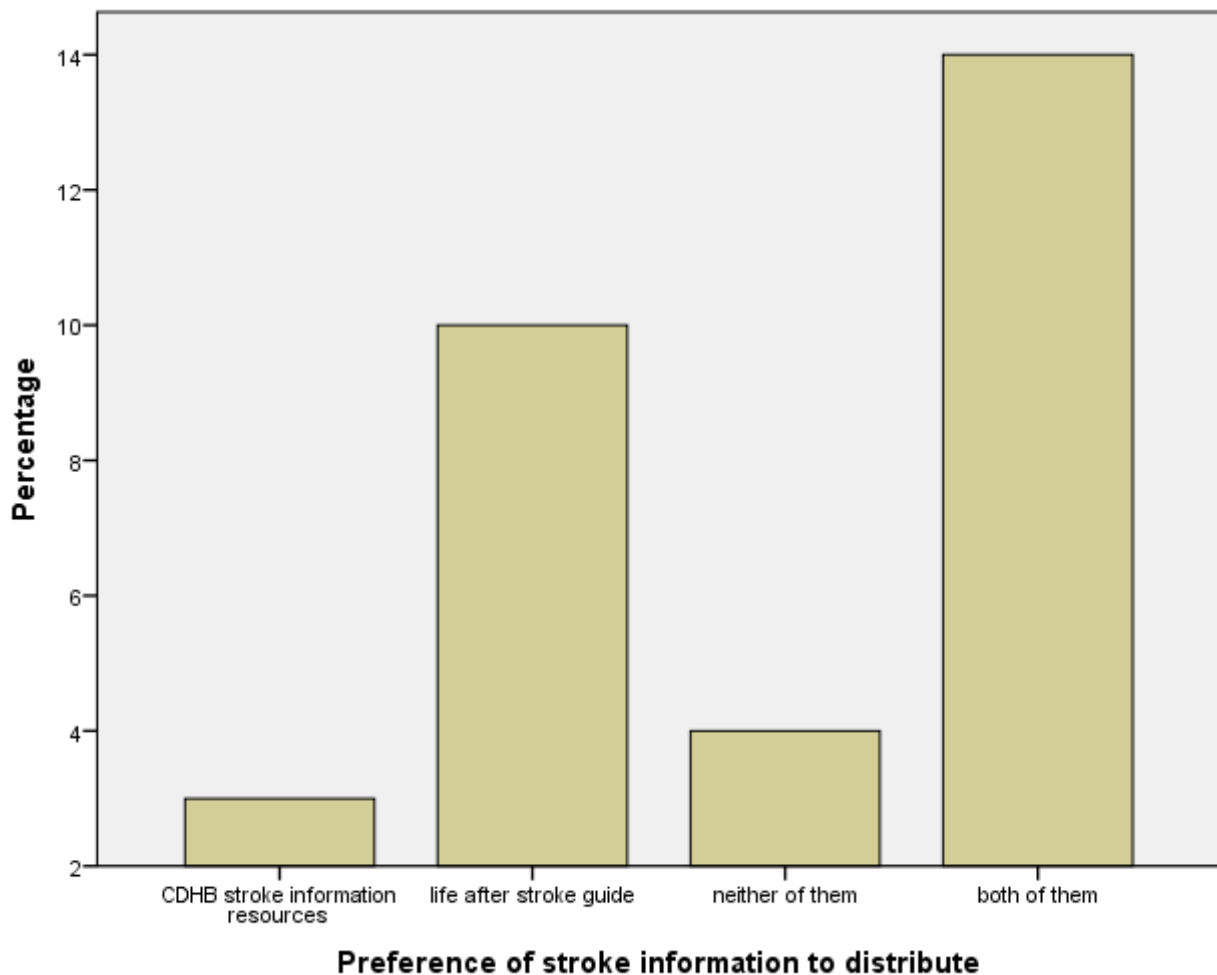


Figure 9: Reported staff member's preference of information book for distribution to stroke patients and family members.

From the study, it was also found that the largest proportion of the staff (40.7%) distribute information resources at the time of admission. Approximately a quarter (25.9%) of health professionals distribute information materials if the patient and family members ask for one, and a quarter of the staff members provide when they find that a patient does not have one. The survey found that staff who reported working for longer in their role are more likely to distribute the book than newer staff. In the tables below that staff who have worked for longer than five years in their

profession are more likely to check whether patients have a copy of the book and provide them with one if they do not but new staff tend to distribute information only at the time of admission or if the patient and family members ask them.

Table 5 Comparison between length of staff working and distribution of the book

| Count | | Distribution | | | | | Total |
|--------|--------------------|--------------------------|----------------------------------|---------------------------------------|---|---|-------|
| | | at the time of admission | when the pt/family member ask me | if I find a patient does not have one | at the time of admission and when the patient /family member ask me | at the time of admission, when pt/family ask, if pt does not have one | |
| Length | less than 6 months | 3 | 2 | 0 | 0 | 0 | 5 |
| | 6 months-1 years | 2 | 1 | 0 | 0 | 0 | 3 |
| | 1-2 years | 0 | 1 | 2 | 1 | 0 | 4 |
| | 2-5 years | 3 | 1 | 1 | 0 | 0 | 5 |
| | 5+ years | 3 | 2 | 4 | 0 | 1 | 10 |
| Total | | 11 | 7 | 7 | 1 | 1 | 27 |

Interestingly, from the study, it was clear that the key reason for not distributing the book was that staff did not know where the copies are kept, as reported by 5 out of 7 respondents, answering this question. A second reason provided was that patients and family had not asked for them, which was reported by 4 respondents. One respondent felt it was not their job. Another staff member stated that they are not aware what resources patients have already and where they are in the education process, and two further respondents said that not working full-time had an impact on their distribution of information to patients: for one this means they are not involved in the admission process.

4.2.4 Evaluation of the book

From the survey responses, it was found that more than half of the health professional respondents perceived that the book is very useful but 3.7% of respondents felt it is not useful.

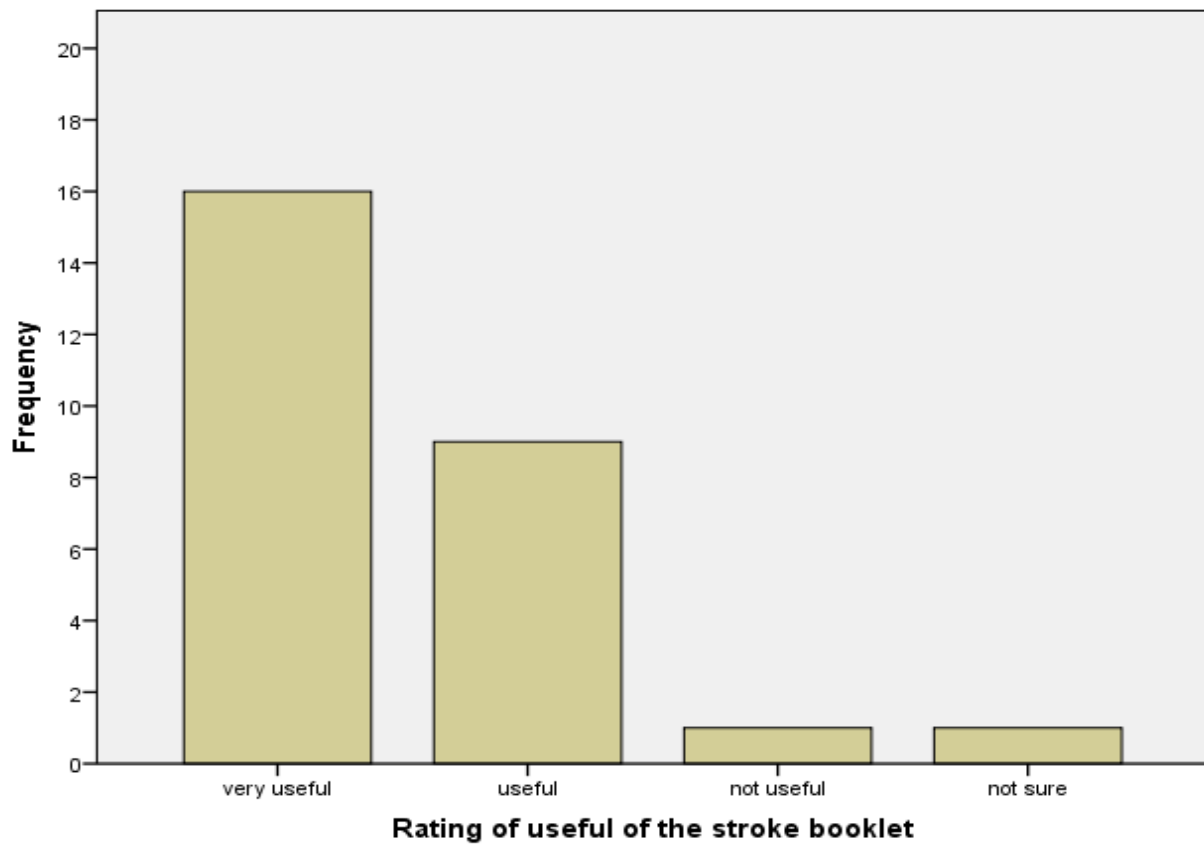


Figure 10: Overall rating of the book *Life after Stroke: a Guide for People with Stroke and their Families*

It was also found that the majority (88.9%) of staff think the words and sentences in the book are easy to understand and only a few are not sure of some of the words (11.1%) and sentences (3.7%). Similarly, 92.6% of participants think the font in the book is of appropriate size, 3.7% think it is too small, and 3.7% are not sure.

The study also found different opinions regarding the information content of the book. Over three quarters (77.8%) of participants think the book has about the right amount of information and relatively few (11.1%) felt it has too much information.

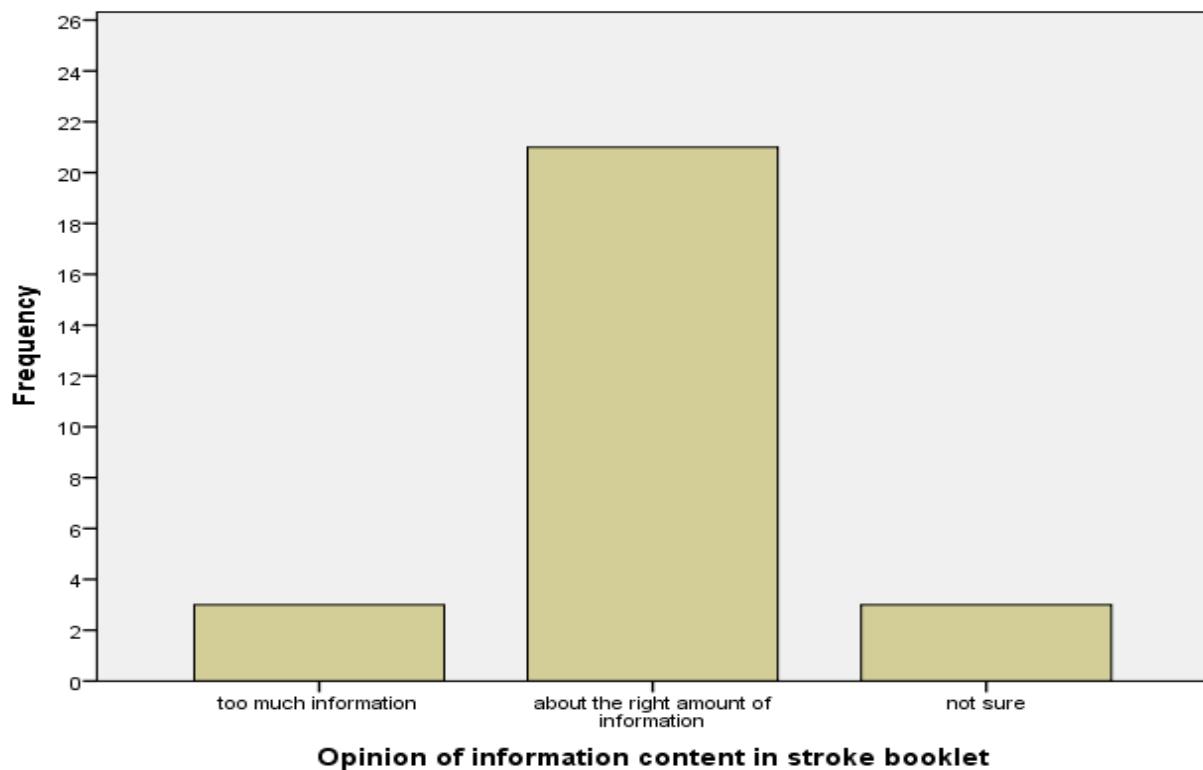


Figure 11: Opinion about the amount of information in the book *Life after Stroke*

From the research, it was also found that although 40.7% of the health professional respondents were happy with the presentation, more than 25% of participants thought it could be presented in a different form and just under third (29.6%) were not sure. Eight participants thought it would be good if the book were displayed on television screens in the hospitals and at GP practices. Six participants thought the book could be displayed on television screens in other public places, six

staff stated it could be presented as a CD/audio and only three participants opted for posters from the social workers and having someone reading the book to patients.

Over half of the staff respondents did not think there needed to be additional information but, a nearly fifth reported a need for examples of experience of stroke studies, regarding recovery, and different kinds of stroke and its likely recurrence.

4.2.5 Comments and suggestions

The survey yielded both positive comments and areas to be improved, identified by respondents

Positive comments include: -

➤ **Quality of content**

Staff were happy to read the science and pathophysiology of stroke, with some staff noting that it is very helpful to get a lot of comprehensive information in one place, which could act as a baseline information package and is, therefore, the preferred resource. Staff participants reported that the book is a simplified form of stroke information suitable to use for stroke awareness and education which gives step by step guidelines of what to expect after stroke. Some staff also think it is an excellent book, well laid out in the simple language and has a glossary of medical terms.

➤ **Value for patients and family members**

Some staff stated that although they have not read the booklet, they have heard positive feedback from family members. Staff also found this book is invaluable for patients and their family members. Its contents are precise and informative and on occasion gives the reader enough information for them to formalise further questions for staff. Because it is in sections, it is easier for the patient, family member, or caregiver to obtain patient information for them personally as opposed to reading the non-relevant material.

Health professional respondents also pointed out areas to be improved.

Suggested areas to be improved included: -

➤ **Design**

One staff respondent stated they *“want to see the book broken up into tabs which would be easier to find sections rather than using an index”*

Another one respondent wished to see pull out section where patients and family members can make comments either about subject matters or questions to ask.

➤ **Content**

One staff member suggested more pictures and photos which would be helpful for understanding and to demonstrate the subject matter. One staff member thought it is too much information if it is given to patients and family members immediately after stroke. It is too much to absorb all at once which could be daunting so it would be great if it were to be simplified. In the same way, one staff respondent suggested to put more cases of experience of stroke into the booklet. One health professional participant also stated: *“considering many strokes have huge cognitive issues a condensed version for some patients may be good and when patients are more alert they can read full version”*. One staff respondent also suggested adding studies regarding recovery and different kinds of stroke and its likely recurrence.

➤ **Font**

One staff participant wished for a larger size font.

4.3 Results of some common variables which are assessed with patients and family members and the staff

Rating of the book

From those participants, who rated the book, (n=52) (26 Patients and family members, 24 staff participants who have read the book, and 2 staff members had not read it, but had rated it, based on listening to the patient's view) 69.8% of participants rated the book *Life after Stroke* as very useful and 26.4% of participants rated the book useful. Only, 1.9 % of participants thought it was not useful.

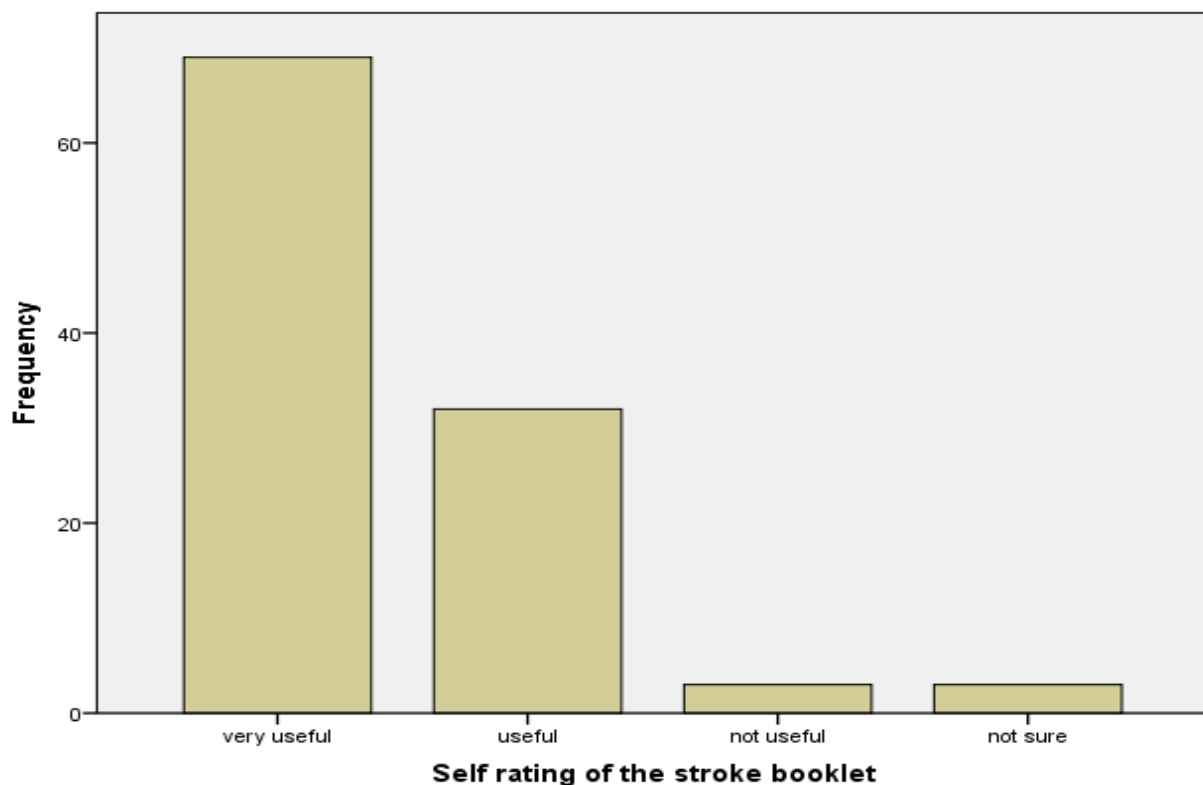


Figure 12: Overall evaluation of the book *Life after Stroke*

Opinion about the book

Similarly, for the overall evaluation rating the majority of the respondents (83%) thought the book has the right amount of information. Just under 10 % of participants thought it contains too much information.

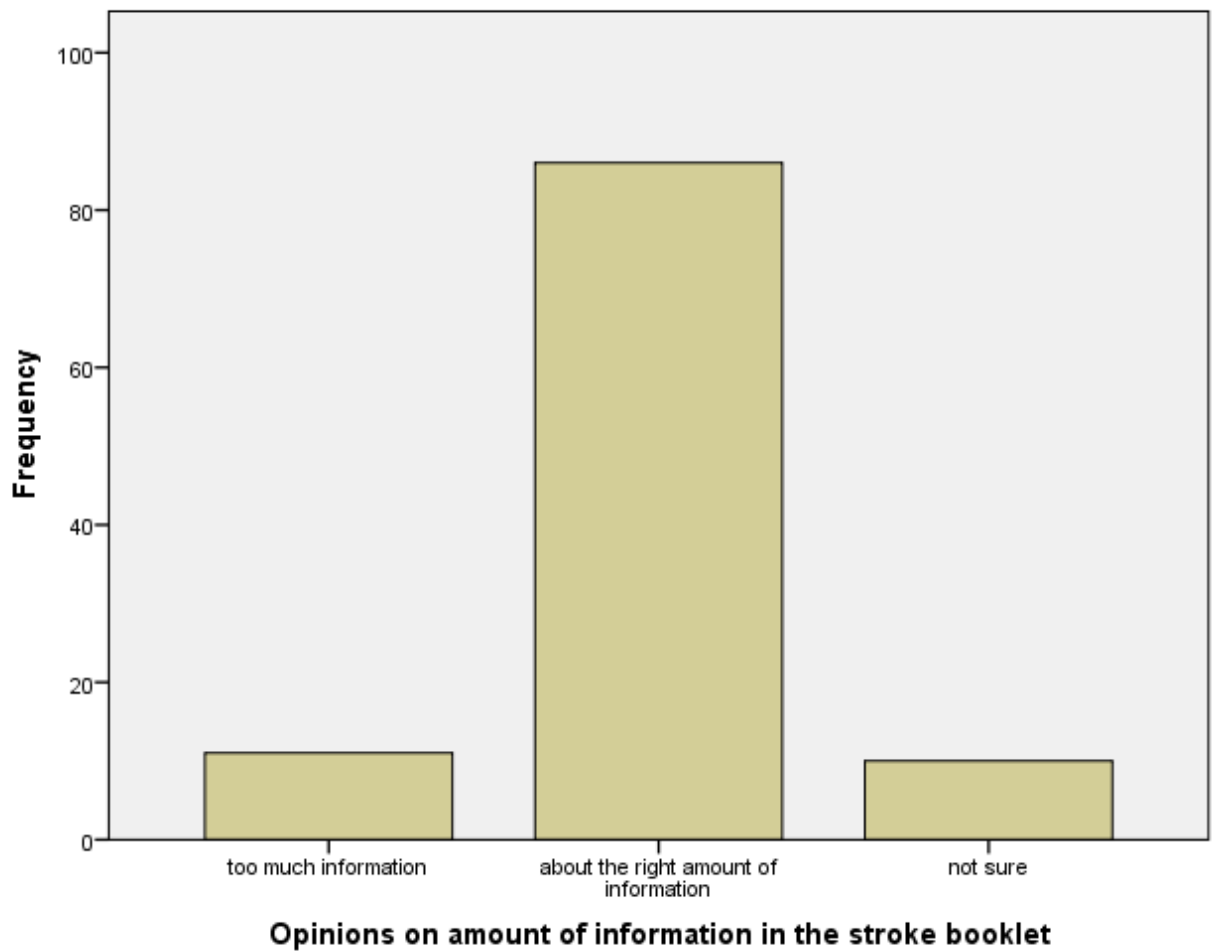


Figure 13: Opinion on amount of information in the book *Life after Stroke*

Understandability of the words and sentences in the book

From the survey, it was also found that the majority (90.6%) of respondents felt the words and sentences in the book were easy to understand. (See Figure 14 and Figure 15).

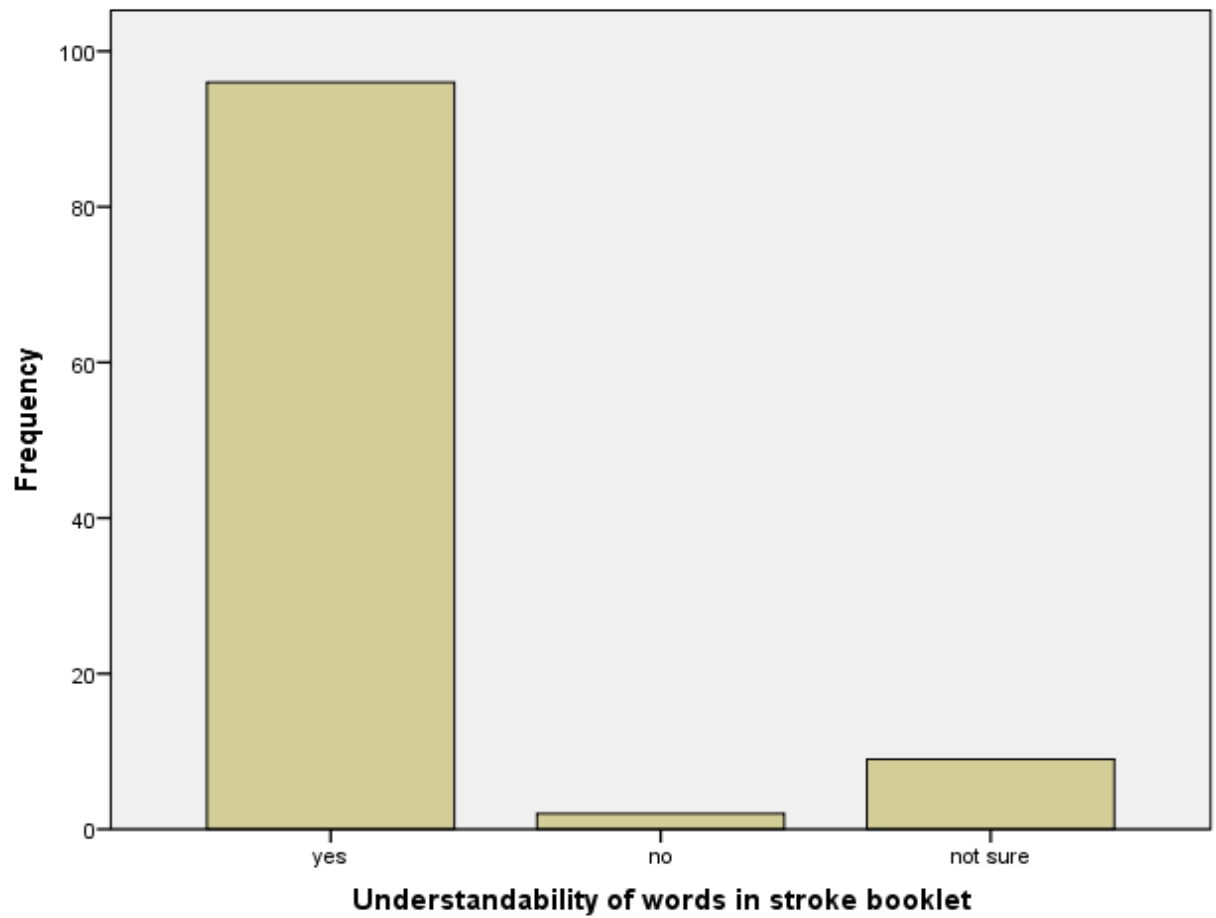


Figure 14: Perceived ease of understanding of the words in the book *Life after Stroke*.

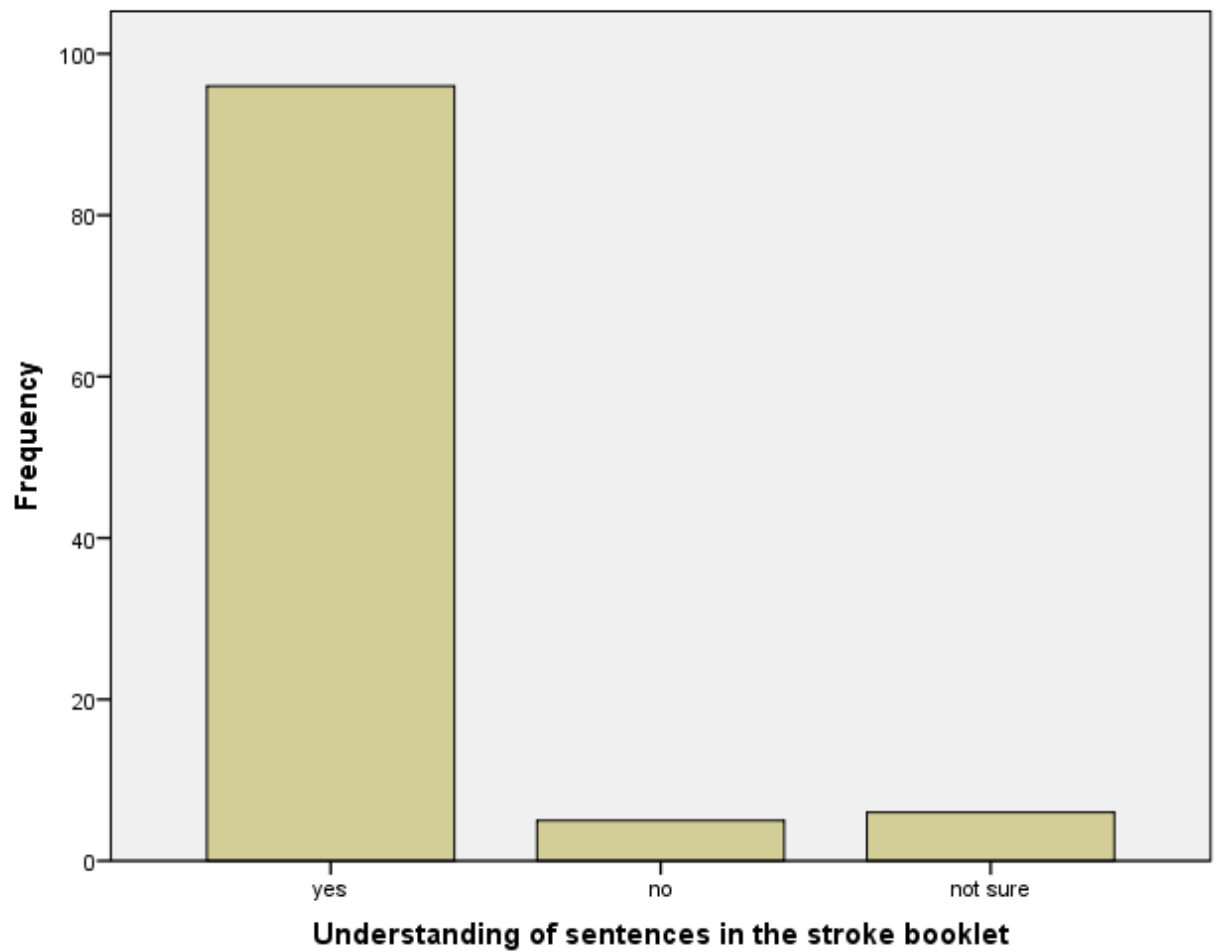


Figure 15: Perceived ease of understanding of the sentences in the *Life after Stroke* book.

Size of the font

The vast majority of participants felt the size of the letters/font in the book was easy to read.

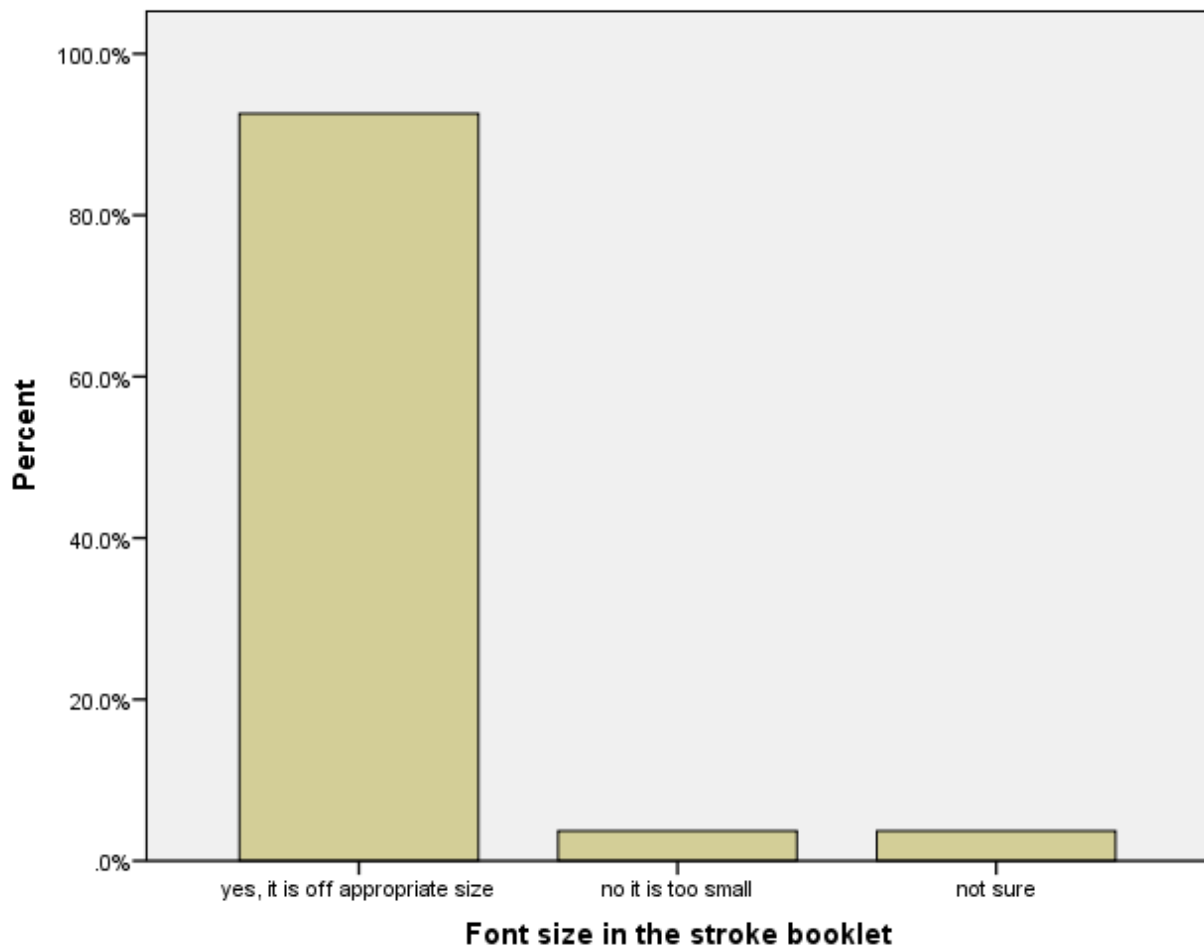


Figure 16: Participants' perceptions of the font size in the book *Life after Stroke*

Knowledge about the electronic version of the book *Life after Stroke*

The survey responses show that approximately two thirds of participants were not aware that there is electronic version of the book. Conversely, just over fifth of participants knew that an electronic version is available.

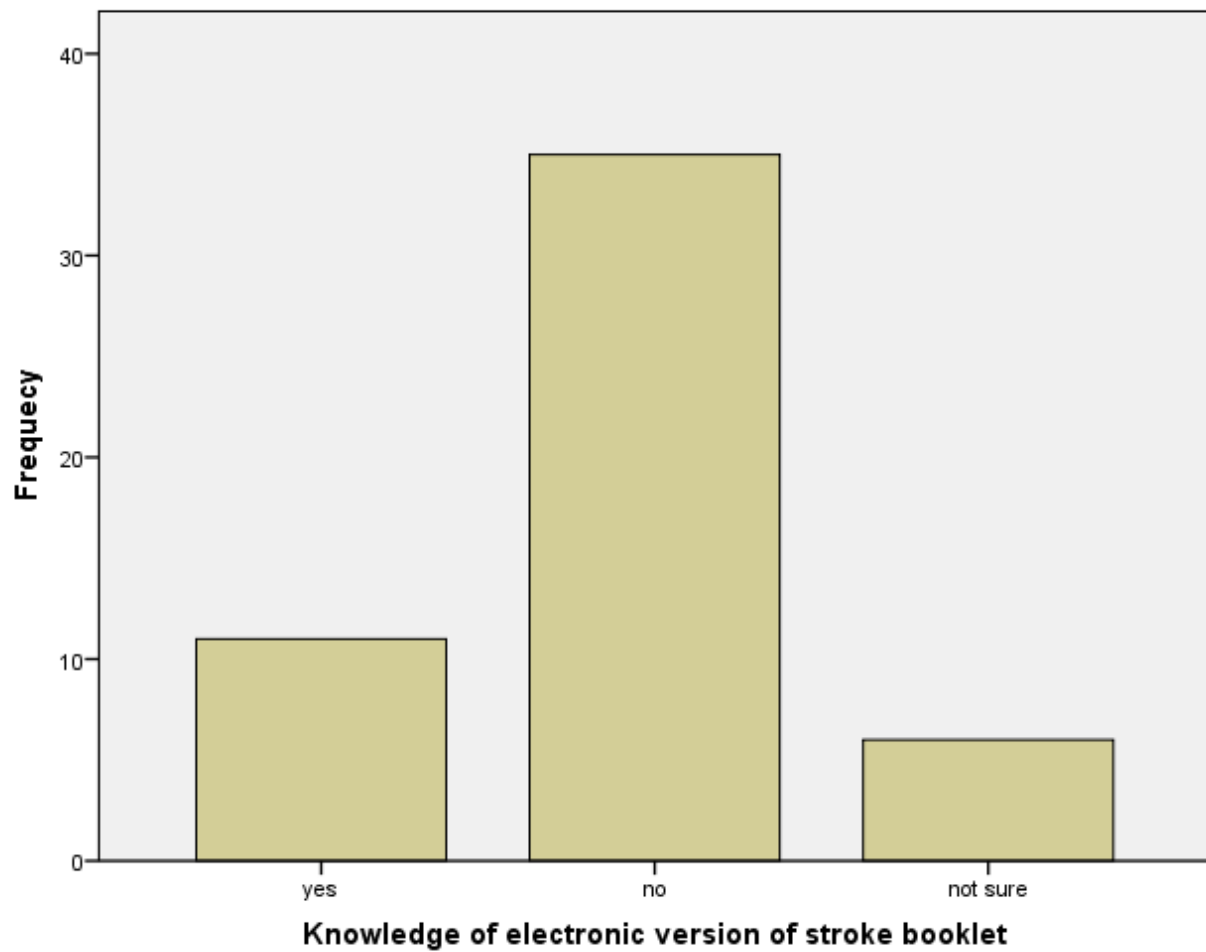


Figure 17: Knowledge about the electronic version of the book *Life after Stroke*

Presentation of the book

There was an equal percentage of participants who thought that the information in the book could be presented in a different format as there were those who think the book's presentation and format is appropriate.

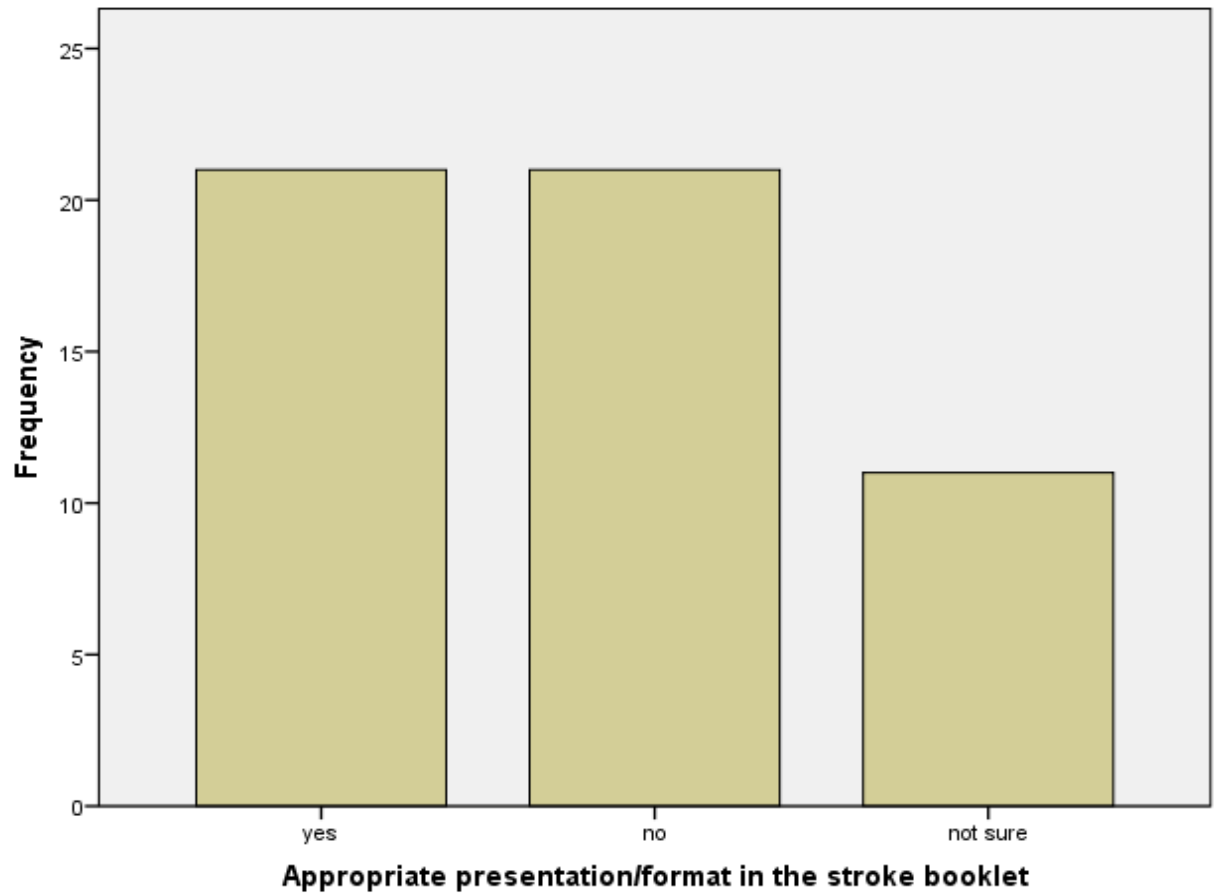


Figure 18. Participants' perceptions of format/presentation of the *Life after Stroke* information.

Chapter 5 Discussion

The results of this study have helped to identify whether and how the information book *Life after Stroke: a Guide for People with Stroke and their Families* is valuable to stroke patients and their family members as well as for health professionals. Survey responses provided information about the distribution of the book and factors affecting this, as well as the impact of reading the book by the intended audience (stroke patients and family members), and an overall evaluation of its acceptability and effectiveness. The study was also able to obtain qualitative comments and suggestions regarding the book, which will be useful for the development of the resource. Despite best efforts to ensure the results are as free as possible from potential problems, these results must be interpreted with caution because the study was conducted only in one ward (restricted to stroke rehabilitation for individuals over 65 years) and the sample size is small.

5.1. Distribution of the book

According to NHB Shetland (2010), and Turnbull (2003), in order to know whether patient information resources are effective, or not, we need to ask to the patients. To evaluate the resources against its purpose and goals, New Zealand Ministry of Health (2012) recommend the following questions:

- How widely have the resources been distributed?
- What is the response from the primary audience in terms of awareness, understanding, and behaviour?
- What changes have there been in the audience and in their behaviour? And,
- What changes have there been in health literacy?

These recommended questions were used in this project to guide the research and survey questions.

From the survey, it was found that the majority (59.1%) of patients and family member participants had received the book, and this compares favourably with the distribution reported by Hoffmann and McKenna (2006), at only 22.8% patients and 41.7% carers received written information. Although the results from my survey show that nearly 60% received the book, there is still a relatively large proportion of respondents (38.6%), who did not receive a copy, and this is a concern. The study was able to identify the reasons behind this. Health professionals are responsible both ethically and legally to distribute health information materials (Rajasundaram, Phillipps, & Clay, 2006). Our study found that some health professionals have not distributed the book because they either did not know about it, or did not know where the books are kept, or they were not involved in the admission process when these materials are usually provided, or they did not consider it to be their job. Patients and family members not requesting the materials was a further reason it was not distributed. None of them said of lack of time. This study finding is different than others finding where they find the reasons for lacking in provision of information were time constraints, resources in different languages (Roy et al., 2015), lack of resources, communication issues with clients, restriction from organization, lack of communication in team and issues on staffing (Gustafsson, 2008).

From the literature to ensure that the book is well distributed, all staff should have in-service education about the resource, where it can be found, when to distribute, what its purpose is, and who is responsible for distributing the book. The training of health professionals is a key strategy for guaranteeing that booklets are distributed properly to the people who need it (New Zealand Ministry of Health, 2012). Raycroft-Malone (as cited in Sing et al., 2015, p.26) also stated it is important to support key people in the health centres with the provision of education to staff, access to resources, information technology, and databases of information resources to develop local

guidelines. Sing et al. (2015, p. 26) added that one of the Knowledge Transfer Team (KTT) members suggested that the specific roles or duties assigned to KTT members would be helpful because there was some confusion as to specific roles inside the team.

To ensure optimal distribution staff also need to feel the book is useful for patients and they should be encouraged to provide feedback about the book. A quarter of the pharmacists and 15% of GPs believed written information might not be suitable for patients with psychiatric problems (Grime et al., 2007) and stroke patients are at a higher risk for different psychiatric conditions, such as post-stroke depression, mood disorder, and dementia (Fixing, Hilty, Chang, & Servis, 2005). From this study, 11.1% MDT members stated that the booklet has too much information for patients in the early stage of their admission when there are cognitive issues. Staff suggested possible improvements, such as additional pictures and photos, the breaking up of the book sections, using tabs, and the inclusion of a section where patients and family members can make comments about a subject covered or write questions they want to ask. Grime et al., (2007) found many health professionals thought written information should be short and simple. In the same way, my survey generated suggestions from MDT members to make the book simple thus reinforcing what has already been reported in the literature. Respondents also made the suggestion to include more case studies and experiences of stroke. If the Stroke Foundation could consider these suggestions and make some changes to the book then staff might feel more encouraged to distribute the book more widely.

5.2. Responses from audience

According to Wienman, (1990) written information can bring changes in patients' knowledge, behaviour, and attitude. My project was also focused on identifying responses to a book by its primary audience, that is, stroke patients and family members. According to the New Zealand

Ministry of Health (2012), different factors can affect the quality of a booklet. These include wording, sentences, amount of the information, design, and ease of access to the resource. In the research I conducted only one participant of the total of 50 participants (stroke patients, family members, and health professionals) who read the book felt that the book is not useful. From this finding, we can assume the book *Life after Stroke: a Guide for People with Stroke and their Families* is one of the useful health information book for stroke patients and family members. The study also shows that there may still need to be some adjustment to the amount of information in the book because nearly 10% of 54 respondents felt that it has too much information.

5.3. Impact on Audience

The study also set out to determine the impact of the *Life after Stroke* book. According to NHS Shetland (2010), research has shown that patients provided with information, regarding tests and treatments, are more satisfied and less anxious than those who were not given that type of information. According to Lomer and McLennan, Dzau, and Bochme (in Hanger, et al., 1998, p. 46) the purpose of stroke education is not only to provide information about the disease but also to empower people who have had a stroke by allowing greater self-determination and coping strategies and also by reducing anxiety. My study also showed that the majority of participants, that is, 19 out of 26 respondents (patients and family members who read the book) felt they have more understanding of the role of rehabilitation after reading the book. Fourteen participants felt they had become more knowledgeable about what is going to happen in rehabilitation, and 12 participants felt more confident about rehabilitation. This finding is also more positive and is consistent with findings of the Roy et al., (2015) study, which found that of the 11 respondents who had received information (written (n=6) and verbal (n=5)), seven were happy saying it had helped them to cope and they were positive regarding the provision of information.

5.4. Was the information valuable?

There are several sections in the book *Life after Stroke*. The study explored the sections and the information provided in the book that were helpful to patients and family members. According to report by McKevitt et al. (2010) about 50% of stroke survivors' and carers' information needs were not met. These included diet, benefits entitlement and its access, holidays for people with disability, aids and adaptations for the home, as well as information about driving and employment. The findings in my project are consistent with the findings of Andrew et al. (2013) who found that 80% of respondents received enough information about strokes. It is good have found in my study that a large proportion (80.8%) of the 75 respondents thought that *Life after Stroke* is useful. Respondents (patients and family members) felt all sections in the book were useful. It was positive to find most of the participants felt, the *goals* section in the book was very useful. The second very useful section was *how damage to different parts of the brain affects different functions* and the third very useful section was *helping to prevent stroke*. In the same way, many respondents, (18 out of 26) felt that the relationship, *restlessness* and *organising the day* sections were useful. A few respondents did not read all sections of the book and a few thought some sections were not useful.

In contrast, more than half of the participants (15) who read the book felt the *stroke in younger people* section was not applicable. It is quite understandable that participants would feel that section was not applicable to them because the study was conducted in an older person's health setting. Most of the respondents who did not read all sections of the book (n=4) indicated those sections were not relevant to their condition. The respondents who did not read all sections were patients.

5.5. Preference and Presentation

According to Morris and Groft (as cited in Wienman, 1990) 75% of respondents prefer written information and over 80% of respondents read written information. Rogested et al. (2003), and Hoffmann and McKenna (2005), reported that patients welcome written information because it helps them to understand and aids in decision making. My study also found that 90% of participants (patients and family members) prefer to read paper resources, but the research was also able to identify whether participants are aware of the electronic version of the book *Life after Stroke* or not. The first version of the booklet was available only in paper format and the second version is available in electronic format as well. The majority of participants (67.3%) were not aware of the electronic version of the book, and this is also a concern. There is a risk that if consumers seek information from the Internet they may be getting wrong information from wrong website and in these situations health professionals need to be prepared to communicate and answer patients' questions (Gauld and Williams, 2009). Although, this result may be different in the setting of the younger stroke victim ward staff need to know about the electronic version of a book and this needs to be offered to patients and family members because the pilot project of RNZFB in 2009 has already shown that senior citizens also welcome digital materials. But for this staff need to be aware of the electronic materials first. There should be training to health professionals in school where they do their training and patients needed to be guided to validated Internet resources (Gauld and Williams, 2009).

Information should be provided in various formats such as verbal, written, and pictorial to improve accessibility of information. These types of information should be available through telephone, fax, email, text message, mail delivery by post, and on the web (Dickinson, Raynor, Kennedy, Bonaccorro, & Sturchio, 2003). Furthermore, Rogested et al., (2003), mentioned that to meet the

expectation of health consumers, the information provided should be in the right format for patients to understand it. My research also found that half of the participants think that the information could be presented in different formats. Although written information is very self-explanatory and helpful and easy to recall (Garrett and Cowdell, 2005), it may not be a good resource for people with cognitive impairment or age-related vision loss (Edwards, as cited in Du, Ma, & Li, 2016). People with strokes may easily listen or watch video materials at their own pace (Huang as cited in Du, Ma, & Li, 2016). The Stroke Foundation might also need to consider providing patient information in video format in television for hospitals and GP practices as well as other public areas because patients and family members (n=7) also reported that information could be presented in different formats. If the Stroke Foundation act on this feedback Māori can also benefit because, according to Barker-Collo, Feign, Parag, Lawes, & Senior (2010) inspirational stories of Māori and Pacific people with stroke in the DVD had address the information provision issue and led in improvement in physical summary score and whānau ora scores (Barker-Collo et al., 2010). One staff member suggested that a poster, such as the one used by the social worker would be nice. One staff member stated that a person reading book to the patients, recorded on CD, might be good idea for the patients who have lost their vision due to stroke.

5.6. Feedback

According to Parrinelo (1984) feedback from the patients and families is valuable because it can be utilised to modify and revise teaching aids so that the learning needs of patients and families can be met. In my study I was also able to obtain feedback from patients, family members, and health professionals which might be useful for the Stroke Foundation if it is planning to publish a forthcoming edition. Apart from positive feedback there is also feedback, regarding areas to be improved. Information needs of patients and caregivers may be different according to the stages

and harshness of the stroke (Hassan, Aljunid, & Davis, 2012). Additional topics for each participant are different. Some respondents wanted few topics whereas others wanted nearly all of the topics (Hoffmann and McKenna, 2006). In my study, we found that the patients and family members were suggesting a shorter version, perhaps of two to three pages that could be given to all visitors and stroke patients, particularly early in their stay in hospital. In a systematic review done by Greenwood, Mackenzie, Cloud, and Wilson (2009) it was found that a commonly identified need was for information and training. The information needed ranged from general information on strokes, such as the possibilities of further strokes, to financial entitlements and local services, and secondary prevention. Kerr, Hilari, and Litosseliti (2010); Wiles, Pain, Buckland, and McLellan (1998); Perry and Middleton, (2011) also found both people with a stroke and their carers wanted information on practical issues, such as information about driving, social clubs, sex, and further employment. A need for information on sexual relationships was also reported by 18% of respondents in a study by Andrew et al., (2013). People with a stroke may have other co-morbidities, for example, cognitive impairment, osteoarthritis, vascular diseases, and social issues such as isolation and loneliness. For this reason, one recommendation is to provide information, regarding support and help they need (Royal College of Physicians, 2016). My study respondents also noted a need for more information about stroke clubs and what they offer, information about grants, and time frames for financial assistance. The need for information about services and benefits was also found in Eames et al., (2011). Other information stroke patients and caregivers might be wanting are community referrals and emotional support, information on depression and, in terms of presentation, they also want shorter phrases and bulleted notations (Rochette, Korner-Bitkensky, Tremblay, and Khoda (2008). The research participants in my study stated that they wanted a little bit more information about double vision. But, no one asked for

information on sexual relationships. This request, however, may be presented in younger people with stroke. The Department of Health/Vascular Programme/stroke (2007) suggested information be provided in different ways for instance as diagrammatic material, or verbal information, and in my study one staff respondent suggested the use of more pictures and photos as illustrations. Meade (n.d.) also found that pictures, comics, cartoons, and stories, combined with simple language with positive messages were wanted in a resource by patients with stroke. The visual component of a book can make information more memorable and the sentences in the book provides the information (McNicol, 2014). Another one staff member suggested breaking the book into tabulated sections to make it easier to find a section. In the same way, three other staff respondents suggested a simplified version, a pull out section, and to put more case studies of those who had experience of stroke as well as studies about different kinds of stroke, its likely recurrence, and about recovery. Education to patients, family members, and caregivers is a vital part of stroke care. Integrated and coordinated education should be provided appropriately (Lindsay et al., 2008). The recommendation of National Clinical Guidelines (UK) is to assist stroke patients' carers in adapting to their new role by offering education programmes before discharge, preparing for transfer with all the necessary equipment and support and information about appropriate local statutory and voluntary agencies. (Mackenzie et al., 2007). In New Zealand the Stroke Foundation can also help people with strokes and family members' information needs as reported by the study respondents.

5.7. Comparison with other New Zealand research

A cross-sectional descriptive survey design was used, similar to that used by Roy et.al. (2015), to ascertain the value of the *Life after Stroke* book. Some findings were similar and some were different from those reported by Roy and colleagues. Both that research and the findings of my

research indicate that the Stroke Foundation resources are the preferred resources. In both research projects, staff were not aware of the availability of resources, but whereas in my research one staff member thought distribution of the book is not their job, Roy and colleagues found some staff were thought that the resources were only for staff training. In Roy and colleagues 2015 research staff suggested the book should be available in a different language but this was not suggested by the participants in my research. In both research projects, staff suggested making the resources available on DVD. In addition, in my research staff suggested that the book be recorded on a CD and also that it should be displayed on a television screen in a range of settings. In both the 2015 Roy et al. research and in mine a staff stated it would preferable not to provide information in early admission phases to patients or family members because they are not able to absorb the information. In both Roy's 2015 research and in mine for a few participants the information was frightening but for others it provided strength. The study has both strengths and limitations which will be discussed below.

5.8. Strengths and limitations of the research

5.8.1 Strengths

This research has supported other research which has ascertained the value of the information book produced by the Stroke Foundation of New Zealand and provided feedback on its publication. It has also helped to identify the information needs of older people with stroke and their family members/caregivers. The main strength of this study is that it was able to include stroke victims. Furthermore, this study was able to obtain an overall evaluation of the *Life after Stroke* book as well as an evaluation of each section of the book. The study was also able to ascertain suggestions from a range of family members, patients, and MDT members for the improvement of the book.

5.8.2 Limitations

The sample size was limited due to different reasons, including the movement of the ward part-way through data collection from The Princess Margaret Hospital to Burwood Hospital, both in Christchurch but on opposite sides of the city. There were also fewer admissions than expected, and more patients, who were more acutely affected by stroke, which restricted their ability to participate in the project. Moreover, it was not possible to extend data collection because of time and budgetary constraints. In addition, the study was not able to include stroke patients within the community or younger stroke patients (that is, stroke patients aged under 65 years of age). Only English-speaking participants were included, which limited the ethnic diversity of the sample. Furthermore, in the questionnaire there was no question that related to the number of stays in hospital, the appropriate time to provide information, and which stroke (first, second, or third time) and the type of stroke. All of this data would have been very informative. These limitations could be addressed in further research.

5.9 Recommendations for practice

For hospital management

After admission to the hospital and during their hospitalisation period patients may need detailed information to understand the process of stroke, its meaning and the nature of the disease, and its influence. Patients may also need to know about the treatment plan, its outcome, the future, recovery, and advice to eliminate bad habits, such as smoking (Garrett and Cowdell, 2005). There is no one approach which is considered the best method in provision of health information (Hoffmann and Cochrane as cited in Du, Ma, & Li, 2016). Gustafsson (2008) has suggested to health professionals to establish a system and to make sure information materials are provided as per personal need. One of the strategies of distributing and communicating health information is

to think about the training provided to the health professionals and who should distribute information materials, and also where these materials are available from (New Zealand Ministry of Health. 2012). This is important because when it is unclear whose role it is to provide the information, patients with strokes and caregivers may be uncertain about who to ask for help (O'Mahony, Rodgers, Thomson, Dobson, & James (1997). This strategy ought to be used by hospital management. The inter-disciplinary team self-learning package developed by the Stroke Service Development Christchurch Hospital Group in 2015 and later amended by Ward DG about strokes and how to deal with stroke patients and their families and who to contact for different kinds of problems is also useful (Self-learning Package, 2016). There is, however, the problem that the place where the books are kept, keeps changing so when staff go to get it for patients they can't find it out and then don't give it out to patients. Also the staff self-learning package does not address whose role it is to distribute health information and where the information is to be kept. According to Gustafsson (2005) identifying a key member to take responsibility for finding the information can help in developing information service. This means that in an orientation package for new staff who work in the stroke ward there should be a section about the availability of stroke information materials. This is important because one of the issues behind not distributing booklet was staff not thinking that it was part of their role. Regular reminders about book distribution could be issued in staff meetings.

For the Stroke Foundation

Patients should be actively involved in considering their preference for health information. The personal concerns of patients should be addressed while developing, structuring, and recommending information materials. At the same time patients' information needs, should be assessed continually and revised information provided as a matter of course (Rodgers, Bond, &

Curless, 2001). Parrinello (1984), has also recommended revising and modifying teaching materials to meet the information needs of stroke patients and their families, and for this feedback from patients and families is necessary. Although, this research has been conducted in a single rather than multiple settings, the Stroke Foundation could use the findings from this study to inform the development of a future edition of *Life after Stroke: a Guide for People with Stroke and their Families*.

5.10 Recommendations for future research

In future research, recruiting stroke patients, their family members, and health professionals from community care/services and in younger stroke patient settings, as well as across several regions or settings, could be undertaken. A longer data collection time might mean that there was an increase in the number of participants. Similarly, other limitations of this research, such as finding the appropriate time to provide information and including respondents who speak different languages could be addressed in future research. The researcher might also compare the *Life after Stroke: a Guide for People with Stroke and their Families* with CDHB stroke information resources as well. Future research could also compare the online resources and paper resources of the Stroke Foundation. Because this information book is used by different ethnic group of patients and their family members, all patients should be targeted to evaluate the book, for example, Māori, Chinese, and Pacific Islanders. There is also a continued need for information after discharge as well. Carers voiced that they had expected information by health care professionals and availability of information packs according to their situation (Mackenzie et al., 2007). Based on this future research could examine whether the discharge information needs are met or not through the Stroke Foundation information resources. Research could investigate the overall stroke survivor needs and can include respondents who had stroke from one to five years previously. Research could

also use qualitative methods to evaluate the book so that respondents can outline more in depth different information needs in their stroke rehabilitation journey. A researcher could also compare stroke patients and carers' reading ability with the reading level of the written information.

Chapter 6 Conclusions

In conclusion, this study was able to evaluate the book *Life after Stroke: a Guide for People with Stroke and their Families* by using a cross-sectional survey method to obtain feedback about the book which hasn't taken place since the book was published. The study found that the book *Life after Stroke* is a valuable information resource for stroke patients and their family members. It was found that this book has had a positive impact on the target audience. However, as reported by participants, there are still some areas to be improved in the content, design, font, format and presentation. Since the book was published it was not known whether staff are aware of its availability for patients, if they are they distributing it or not, if not what are the reasons, which have not studied before. Till now a lack of time and budget were identified as the reason for not distributing written information but this study was able to find additional reasons as well for the information book not being widely distributed, such as not knowing where the books are available, not participating in the admission process (because the staff are working on a casual basis), patients and family members not asking for a book and staff being unclear about who is distributing the book. Many participants are unaware about an electronic version of the book but many preferred to read paper resources. Although, the sample size is small and only one ward was used to collect the data the result must be treated with caution, however the findings will certainly be very useful to hospital management and the Stroke Foundation to make the book accessible to patients with stroke and their family members.

More organisational work is needed to make the book more widely distributed. For this to occur a concerted effort is needed from the different sectors. For example, the Stroke Foundation could use the feedback from this research to revise the book and hospital management could help by

providing in-service education to staff, reminding staff in staff meetings to distribute the book, and adding the stroke book to the orientation package for new hospital staff.

In future, I hope all the written information for stroke patients and family members will be prepared by consulting stroke victims and their family members along with the health professionals and evaluated on a regular basis to amend as per the changing needs of the patients and their family members.

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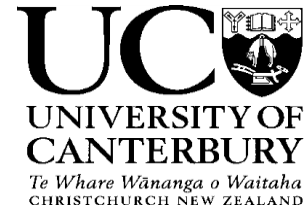
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Appendix A: Informed consent for participants

Consent Form



Department: School of Health Sciences

Telephone: +64 210442351

Email: gsh53@uclive.ac.nz

Date:

A cross-sectional survey of people with stroke, their family members and Multi-Disciplinary Team health professionals regarding the value of the information book: A guide for people with stroke and their families.

Consent form for the study participants completing the life after stroke book evaluation survey.

☐ I agree to participate in this survey conducted by Gargi Sharma Thapaliya from the above institution. I understand the purpose of this study is to find how health professionals, stroke patients and their family members use the book **“Life after stroke a guide for people with stroke and their families”**. The survey will ask my opinion about the book, find out if patients and family members are getting the information they want and to get comments and suggestions to improve the book.

I have been given a full explanation of this project and have had the opportunity to ask questions.

I understand what is required of me if I agree to take part in this research.

I understand that participation is voluntary and I may withdraw at any time without penalty.

Withdrawal of participation will also include the withdrawal of any information I have provided should this remain practically achievable.

I understand that all data collected for the study will be kept in locked and secure facilities and/or in password-protected electronic form and will be destroyed after five years.

I understand that this study will determine if the information book “Life after stroke: a guide for people with stroke and their families” is valuable to stroke patients and family members as well as health professionals and what are their comments and suggestions on the book

I understand that I am able to receive a report on the findings of the study by contacting the researcher Gargi Sharma Thapaliya at the conclusion of the project

Please tick the box provided if you would like to receive a summary of results

YES ☐

NO ☐ If yes, name/address

I understand that I can contact researcher Gargi Sharma Thapaliya gsh53@uclive.ac.nz or the supervisor Professor Ray Kirk ray.kirk@canterbury.ac.nz for further information. If I have any complaints, I can contact the Chair of the University of Canterbury Human Ethics Committee, private Bag 4800, Christchurch humanethics@canterbury.ac.nz

By signing below, I agree to participate in this research project.

Name: _____

Date: _____

Signature: _____

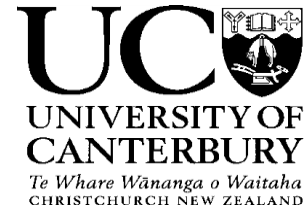
(Please return the completed consent form along with the survey questions to Gargi Sharma Thapaliya or to the in-charge of the duty of the shift of Ward 2A of The Princess Margaret Hospital)

Researcher,

Gargi Sharma Thapaliya

Appendix B: Information sheet for participants

Information Sheet



Department: School of Health Science

Telephone: +64 210442351

Email: gsh53@uclive.ac.nz

Date:

A cross-sectional survey of people with stroke, their family members and MDT health professionals regarding the value of the information book and life after stroke: a guide for people with stroke and their families.

Information sheet for the study participants completing the life after stroke book evaluation survey.

You are invited to participate as a subject in this research survey on the evaluation of the book 'life after stroke: a guide for people with stroke and their families'.

The research aims to find how health professionals, stroke patients, and their family members use the book "**Life after stroke a guide for people with stroke and their families**". It will get their opinion about the book, find whether the patients and family members are getting the information they want and to get comments and suggestions to improve the book.

My involvement in this study is for the purpose of conducting research and data collection in this study. This is to find if the information book “Life after stroke a guide for people with stroke and their families” valuable to stroke patients and family members as well as health professionals and what are their comments and suggestions on the book.

Your involvement in the project is to read each question and provide the best answer that suits you. The survey has approximately 20 questions over 10 pages which will take approximately 15-30 minutes to complete.

The results of the research will be reported as a master of health sciences thesis, but you may be assured of the complete confidentiality of data gathered in this investigation: the identity of participants will not be made public it will remain anonymous, only aggregated data will be published. To ensure anonymity, data will be coded and locked away in the filing cabinet in a locked office at the University of Canterbury and later transferred to a laptop for data analysis and report writing.

You may receive a copy of the project results by contacting the researcher at the conclusion of the project. Participation is voluntary and you have the right to withdraw at any stage without penalty. If you withdraw, I will remove information relating to you up to the point where the analysis of the data commences. If you like to contact Māori health support person in the process of data collection, then you may contact to Eru Waiti, Team Leader, Māori Health Services, eru.waiti@cdhb.health.nz.

The project is being carried out as a requirement for a course degree of Master of Health Sciences by Gargi Sharma Thapaliya under the supervision of Professor Ray Kirk and Lecturer Annabel

Ahuriri. They will be pleased to discuss any concerns you may have about participation in this project.

A thesis is a public document and will be available through the University of Canterbury Library. Any data will be kept by the University of Canterbury and destroyed after five years.

This project has been reviewed and approved by the University of Canterbury Human Ethics Committee, and participants should address any complaints to The Chair, Human Ethics Committee, University of Canterbury, Private Bag 4800, Christchurch (human-ethics@canterbury.ac.nz). This project has also been reviewed and approved by Local authority of Canterbury District Health Board and CDHB research consultation of Māori.

If you agree to participate in the study in the study, you are asked to complete the consent form and return it to the researcher, Gargi Sharma Thapaliya, along with the completed questionnaire.

Appendix C: Questionnaire for patients and family members

Questions for patients and family members

Life after stroke a guide for people with stroke and their families Booklet Questionnaire

My name is Gargi Sharma Thapaliya, I am from the School of Health Sciences, University of Canterbury, Christchurch, New Zealand. I am conducting a study as part of my Master in Health Sciences degree. The purpose of this study is to ascertain the value of booklet “Life after a stroke a guide for people with stroke and their families”. In order to find out the value of the booklet we are interested in answers to the following questions:

1. What effect/s did stroke patient and family feel after reading the book?
2. What types of information do patients and families report as helpful and not helpful?
3. What learning needs are reported by the study patients and families that are not being met through the use of the booklet?
4. What is the overall rating of the book “Life after Stroke a guide for people with stroke and their families”.

It is hoped that your participation in completing this questionnaire will help and benefit nursing/healthcare in New Zealand. If this book can provide all the information requirements according to families’ and patients’ needs, then nurses can spend more time with the patients and participate in their rehabilitative goals and nurses can also get support from family members

during the rehabilitation period. Furthermore, stroke patients' rehabilitation time may improve or shorten.

The survey should take no longer than 15-20 minutes to complete. I can assure you that your name will not be shared with anyone else and your answers to the questions will be combined with answers from other survey participants so that no one will identify the answers that you provide today as belonging to you. Your privacy is protected and I can assure you that your answers will be kept confidential.

1. Have you been given a book stroke?

☐ Yes

☐ No If no, please go to question number 16.

☐ Not sure

If yes, who gave this booklet to you? *(Please tick the box that applies to you.)*

☐ Doctor

☐ Nurse

☐ Social worker

☐ Occupational Therapist

☐ Physiotherapist

☐ Speech-language therapist

☐ Dietitian

☐ Stroke foundation community strike advisor

☐ Other, please state_____

Which book you have been given?

- ☐ Life after Stroke: a guide for people with stroke and their families
- ☐ CDHB stroke information resources

2. Where did you receive this book? *(Please tick the box that applies to you.)*

- ☐ Christchurch Public hospital emergency department
- ☐ Christchurch Public hospital ward 24 (acute medical assessment unit)
- ☐ The Princess Margaret Hospital Rehabilitation ward (ward 2A)/ Burwood hospital ward DG
- ☐ At home
- ☐ Other, please state_____

3. Do you know you can get this book in electronic form as well? *(Please tick the box that applies to you.)*

- ☐ Yes
- ☐ No
- ☐ Not sure

4. Which type of book do you prefer to read? *(Please tick the box that applies to you.)*

- ☐ Electronic resources (online, on computer/tablet)
- ☐ Paper resources
- ☐ Other, please state_____

5. Do you think the words in the book are easy to understand? *(Please tick the box that applies to you.)*

☐ Yes

☐ No there are lot of medical terms which I cannot understand

☐ Not sure

6. Are the sentences in the book easy to understand? *(Please tick the box that applies to you.)*

☐ Yes

☐ No

☐ Not sure

If no what is the cause?

☐ Too long

☐ Too complicated

☐ Other, please state_____

7. Do you think the font (size of the letter) in the book is easy to read? *(Please tick the box that applies to you).*

☐ Yes, it is of appropriate size

☐ No, it is too big

☐ No, it is too small

☐ Not sure

8. In your opinion, do you think this book is: *(Please tick the box that applies to you.)*

- ☐ Too much information
- ☐ About the right amount of information
- ☐ Not enough information
- ☐ Not sure

9. Did you find the information you were looking for in the book? *(Please tick the box that applies to you.)*

- ☐ Yes
- ☐ No

If no what is missing? _____

.

After reading this book, I was able to: *(Please tick all the boxes that apply to you.)*

- ☐ More confident about rehabilitation
- ☐ Better able to manage my emotions
- ☐ More understanding of my role in rehabilitation
- ☐ More knowledgeable about what is going to happen in rehabilitation
- ☐ No change
- ☐ Other, please state _____

10. There are several sections in the book. How **useful** do you find each of the following parts?

(Please tick one box for each part of the book listed below.)

| | Very useful | Useful | not useful | Did not read | Not Applicable |
|--|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| The first week (colour code green) in the book | | | | | |
| <p>➤ Information on stroke (<i>for example what you need to know immediately after stroke, hospital procedures, how it happened and plan for the future after stroke</i>)</p> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| The effect of stroke (colour code pink) in the book | | | | | |
| <p>➤ How damage to different parts of the brain affects different function? (<i>For example, if left side of the brain is affected then right side of the body loses the power</i>)</p> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| <p>➤ Day to day difficulties can result from stroke (<i>For example, not being able to distinguish objects from their background such as not seeing the white cake of shop on the white sink top</i>).</p> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| <p>➤ Practical recommendations for coping with functional problems caused by a stroke. (<i>For example, placing a ruler under the line being read to reduce visual clutter</i>).</p> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

| | | | | | |
|--|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| The rehabilitation experience (colour code orange) in the book. | | | | | |
| ➤ Introduction of the rehabilitation process (<i>such as its meaning, process etc.</i>) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| ➤ Therapy (<i>eg who is coming to treat with movement and balance problem</i>) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| ➤ Reaction to any loss after stroke (<i>for example an individual's shock after knowing the fact he/she has had a stroke</i>). | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| ➤ Stroke and the family/whānau (<i>For example, the disruption experienced by family members after stroke</i>) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| ➤ From hospital to home (<i>for example, home visit and home leave during hospitalisation and discharge planning</i>). | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| ➤ Stress (<i>for example, warning sign of stress and how to deal with stress</i>). | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| ➤ Tiredness (<i>for example, why we get tired after stroke and what helps</i>). | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| ➤ Restlessness (<i>the causes</i>) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| ➤ Depression (<i>why stroke patient gets depressed and what helps to treat depression</i>). | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

| | | | | | |
|---|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| ➤ Frustration (<i>why stroke patient gets frustrated and what helps to alleviate frustration</i>). | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| ➤ Problem-solving (<i>for example, how to solve the problems experienced after stroke</i>). | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| ➤ Relationships (<i>for example, how to maintain relationship with family and friend after stroke</i>) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| ➤ Goals (<i>how to set goals during rehabilitation, for example, progressing from simple to harder goals such as being able to stand then walking without an aid</i>). | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| ➤ Independence (<i>how a stroke patient can gain independence to do his/her task such as making a cup of tea</i>). | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| ➤ Organising the day (<i>how to make daily living time table after stroke to make the day hassle free</i>). | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| ➤ Returning to work (<i>what helps stroke patient to get back to work, for example, plans a gradual return to work</i>). | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| ➤ Life after stroke for caregivers (<i>things to remember while being the caregiver of a stroke patient, for example, do not take on too much duties, it being normal to experience anger and depression occasionally</i>). | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

| | | | | | |
|--|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| ➤ Stroke in younger people (<i>how can young stroke patient be helped during rehabilitation, for example, teenagers stroke patient need more peer support stroke foundation field officer can be asked to arrange contacts</i>). | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Facts and further experience (colour code blue) in the book | | | | | |
| ➤ Driving after a stroke (<i>for example, who assess the fitness to drive after stroke</i>). | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| ➤ Stroke clubs (<i>facilities included in stroke clubs</i>) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| ➤ Helping to prevent stroke (<i>avoiding risk of stroke, for example, control blood pressure, eat a healthy diet</i>) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| ➤ Eating for health (<i>aim to eat cereals, fruits milk product etc</i>). | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| ➤ Assistance (<i>ask with hospital staff, family doctor, Stroke Foundation, Citizens Advice Bureau, helping agencies such as Work and Income NZ</i>). | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| ➤ Glossary Section | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

11. If you have answered did not read in any of the above questions why did you not read them? *(Please tick all the boxes that apply).*

- ☐ Too long to read
- ☐ I started to feel less confident after reading
- ☐ Difficulty in reading caused by stroke
- ☐ English is not my first language
- ☐ Not relevant to my condition

12. Do you think the information in the book could also be presented in a different format?

(Please tick the box that applies to you.)

- ☐ Yes
- ☐ No
- ☐ Not sure

If yes, what formats do you consider useful? *(Please tick all the boxes that apply.)*

- ☐ Displayed on television screens in hospitals and GP practices
- ☐ Displayed on television screens in other public places
- ☐ CD audio (sound only)
- ☐ Other (please state) _____

13. Is there any additional information you would like to see in the book? *(Please tick the box that applies to you.)*

- ☐ Yes

☐ No

☐ Not sure

If yes, what are they? _____

14. What is your overall rating of this book? *(Please tick all the box that applies you.)*

☐ Very useful

☐ Useful

☐ Not useful

☐ Not sure

15. Please provide any other information, comments and suggestions regarding our patients’

information book “**Life after Stroke: a guide for people with stroke and their families**”? in the space below:

About yourself

This information is for statistical purpose only

16. Are you? *(Please tick the box that applies to you.)*

- ☐ A patient
- ☐ A family member
- ☐ A caregiver
- ☐ Other, please state _____

17. Are you? *(Please tick the box that applies to you.)*

- ☐ Male
- ☐ Female
- ☐ Rather not say

18. What age are you? *(Please tick the box that applies to you.)*

- ☐ 15-24 years
- ☐ 25-34 years
- ☐ 35-44 years
- ☐ 45-54 years
- ☐ 55-64 years
- ☐ 65 years or over

19. Which of ethnic groups do you belong to? *(Please tick the box or boxes which apply to you).*

- ☐ New Zealand European/ Pākehā
- ☐ Māori
- ☐ Samoan
- ☐ Cook Island Māori

- ☐ Tongan
- ☐ Niuean
- ☐ Chinese
- ☐ Indian
- ☐ Other, such as Dutch, Japanese, Tokelauan, *Please state*_____

20. What is your religion?

- ☐ No religion
- ☐ Christian (*please specify*)
 - ☐ Anglican
 - ☐ Catholic
 - ☐ Presbyterian
 - ☐ Methodist
 - ☐ Ratana
 - ☐ Ringatu
 - ☐ Other (*please specify*) _____
- ☐ Buddhist
- ☐ Hindu
- ☐ Muslim
- ☐ Jewish
- ☐ Other religion. *Please print*_____

21. What is your highest educational qualification? (*Please tick box or boxes which apply to you*).

- ☐ None (left school without a qualification)
- ☐ School certificate
- ☐ Sixth form certificate
- ☐ University Entrance
- ☐ High school certificate (7th form or Year 13)
- ☐ Bursary or scholarship
- ☐ Polytechnic qualification
- ☐ University degree/diploma
- ☐ Other (*please state*) _____

If you have not received a book but would like a copy, then please put your name and contact details here and will post one to you:

Name: _____

Address: _____

(please return the completed survey questions to Gargi Sharma Thapaliya or to the in-charge nurse on ward 2A/DG at the Princess Margaret Hospital/Burwood Hospital)

Researcher,

Gargi Sharma Thapaliya

Thank you for completing the survey.

Appendix D: Questionnaire for health professionals

Questions for health professionals

Life after stroke a guide for people with stroke and their families Booklet Questionnaire

My name is Gargi Sharma Thapaliya, I am from the School of Health Sciences, University of Canterbury, Christchurch, New Zealand. I am conducting a study as part of my Master in Health Sciences degree. The purpose of this study is to ascertain the value of booklet “Life after a stroke a guide for people with stroke and their families”. In order to find out the value of the booklet we are interested in answers to the following questions:

1. What effect/s did stroke patient and family feel after reading the book?
2. What types of information do patients and families report as helpful and not helpful?
3. What learning needs are reported by the study patients and families that are not being met through the use of the booklet?
4. What is the overall rating of the book “Life after Stroke a guide for people with stroke and their families”.

It is hoped that your participation in completing this questionnaire will help and benefit nursing/healthcare in New Zealand. If this book can provide all the information requirements according to families’ and patients’ needs, then nurses can spend more time with the patients and participate in their rehabilitative goals and nurses can also get support from family members during the rehabilitation period. Furthermore, stroke patients’ rehabilitation time may improve or shorten.

The survey should take no longer than 15-20 minutes to complete. I can assure you that your name will not be shared with anyone else and your answers to the questions will be combined with answers from other survey participants so that no one will identify the answers that you provide today as belonging to you. Your privacy is protected and I can assure you that your answers will be kept confidential.

1. Are you? *(Please tick one box.)*

- ☐ A doctor
- ☐ A registered nurse
- ☐ An enrolled nurse
- ☐ An occupational therapist
- ☐ A physiotherapist
- ☐ A speech-language therapist
- ☐ A social worker
- ☐ A dietitian

2. Are you? *(Please tick one box.)*

- ☐ A full-time staff member
- ☐ A part-time staff member (permanent pool)
- ☐ A casual staff member
- ☐ An agency staff member

3. How long have you been working in the stroke rehabilitation ward? *(Please tick one box.)*

- ☐ Less than 6 months
- ☐ 6 months – 1 year
- ☐ 1 – 2 years
- ☐ 2 – 5 years
- ☐ 5 years +

4. What age are you? (*Please tick one box.*)

- ☐ 15-24 years
- ☐ 25-34 years
- ☐ 35-44 years
- ☐ 45-54 years
- ☐ 55-64 years
- ☐ 65 years or over

5. Have you heard about the book “**Life after stroke: a guide for people with stroke and their families**”? (*Please tick one box.*)

- ☐ Yes
- ☐ No

If yes, do you know you can get this book in electronic form as well? (*Please tick one box.*)

- ☐ Yes
- ☐ No
- ☐ Not sure

6. Which information book do you prefer to provide to stroke patients and family members?

- ☐ CDHB stroke information resources
- ☐ Life after Stroke guide of (The Stroke Foundation)
- ☐ Neither of them
- ☐ Both of them

If you provide information the information book, when do you distribute it? (*Please tick one box.*)

- ☐ At the time of admission
- ☐ When the patient/family member ask me
- ☐ If I find a patient does not have one

If no, why don't you give the information book to the patients and family members?

(*Please tick all the boxes that apply.*)

- ☐ I do not know where I can find this book
- ☐ I do not think this book is important to them
- ☐ I do not have enough time for this
- ☐ It is not my job
- ☐ Patients and family members never asked me
- ☐ Other

Please specify _____

7. Have you ever read the 'Life after stroke' book? *(Please tick one box.)*

☐ Yes

☐ No

If yes, please answer the following questions.

8. Do you think the words in the book are easy to understand? *(Please tick one box.)*

☐ Yes

☐ No, there are a lot of medical terms

☐ Not sure

9. Are the sentences in the book easy to understand? *(Please tick one box.)*

☐ Yes

☐ No

☐ Not sure

If no, what is the cause? *(please tick all the boxes that apply).*

☐ Too long

☐ Too complicated

☐ Other, please state_____

10. Do you think the font (size of the word) in the book is easy to read? *(Please tick one box.)*

☐ Yes, it is of appropriate size

☐ No, it is too big

☐ No, it is too small

☐ Not sure

11. In your opinion, do you think this book is: *(Please tick one box.)*

☐ Too much information

☐ About the right amount of information

☐ Not enough information

☐ Not sure

12. Do you think the information in the book could also be presented in a different format?

(Please tick one box.)

☐ Yes

☐ No

☐ Not sure

a. If yes, what formats do you consider useful? *(Please tick all the boxes that apply.)*

☐ Displayed on television screens in hospitals and GP practices

☐ Displayed on television screens in other public places

☐ CD audio (sound only)

☐ Other (please state) _____

13. Is there any additional information you would like in the book? *(Please tick one box.)*

☐ Yes

☐ No

☐ Not sure

If yes, what are they? _____

14. What is your overall rating of this book? *(Please tick one box.)*

☐ Very useful

☐ Useful

☐ Not useful

☐ Not sure

15. Which do you **prefer** to provide CDHB stroke guidelines or the “Life after Stroke guide” to the patients and family members? *(please tick one box)*

☐ CDHB stroke guidelines

☐ Life after Stroke guide (The Stroke Foundation)

☐ Neither of them

16. Please note any other information, comments and suggestions regarding the patients’ information book **Life after Stroke: a guide for people with stroke and their families?** in the space below:

(please return the completed survey questions to Gargi Sharma Thapaliya or to the in-charge nurse on ward 2A/DG at the Princess Margaret Hospital/Burwood Hospital)

Thank you for completing the survey.

Appendix E: Approval Letters

Canterbury

District Health Board

Te Poari Hauora o Waitaha

1st March 2016

Gargi Sharma Thapaliya
The Princess Margaret Hospital
Ward 2A

Re: A cross-sectional survey of people with stroke, their family members and MDT health professionals regarding the value of the information booklet and life after stroke: a guide for people with stroke and their families

Tena koe Gargi,

Ka nui te mihi tenei ki a koe me tou roopu o nga Kairapukorero ki te hapai o te kaupapa whakahirahira mou, moku mo tatou katoa. Ko Rapunga Korero te mea nui. No reira tena koe me te roopu o ka Kairangahau, tena koutou katoa.

Thank you for submitting your research for assessment by Te Komiti Whakarite. We have made several general comments for you to consider.

It is important to acknowledge the issues pertaining to ethnicity and to consider how ethnicity data will be collected in your study. Given the issues around ethnicity data collection in hospital databases this information should be collected in demographic information as part of the research. The Census 2013 ethnicity question is the preferred tool in recording ethnicity.

Inclusion of accurate contact details for Māori health support in the study's Participant Information Sheet will be an important addition for those Māori participants enrolled in your study.

Allowing a support person or whānau member to accompany the participant during research interviews/visits/sessions is a positive inclusion that is in keeping with the values of manaaki / caring and tautoko / support and provides an increased security for Māori participants.

Researchers need to be aware of the importance of explaining to Māori participants and/or their whānau how the study/research data will be stored, any security measures, the length of time and the process that takes place up to the destruction of the data.

Dissemination of the study/research findings in a summary form to participants is a user friendly approach to keeping people informed and their contribution valued. Researchers must take care to ensure that Māori participants understand and agree on which information is to be published in what formats and forums.

It is a requirement of the ethics approval process that a final report be submitted when the research is complete. A copy of the report should be provided to me at that time. Te Komiti Whakarite would be willing to assist in the dissemination of your findings once your project has reached a successful conclusion to the appropriate Māori organisations, Māori health professionals and Māori researchers. We are committed to building on-going relationships with researchers in the hope of improving Māori health.

Te Komiti Whakarite

245 Antigua Street, Christchurch, Private Bag 4710, Christchurch, New Zealand
Telephone: (64) (3) 364 0640 Ext: 88474 Facsimile: (64) (3) 378 6018

I hope this letter will suffice in terms of the application. Please contact me should you need any other information that may not have been included in the letter relevant to your research.

Heoi ano



Eru Waiti
Chairperson
Te Komiti Whakarite

HUMAN ETHICS COMMITTEE

Secretary, Rebecca Robinson

Telephone: +64 03 364 2987, Extn 45588

Email: human-ethics@canterbury.ac.nz

Ref: HEC 2016/03

11 March 2016

Gargi Sharma Thapaliya

School of Health Sciences

UNIVERSITY OF
CANTERBURY

Dear Gargi,

The Human Ethics Committee advises that your research proposal “A cross-sectional survey of people with stroke, their family members and MDT health professionals regarding the value of the information booklet and life after stroke: a guide for people with stroke and their families” has been considered and approved.

Please note that this approval is subject to the incorporation of the amendments you have provided in your email of 9th March 2016, and **subject to the finalised survey being submitted to the HEC for review.**

Best wishes for your
project. Yours

sincerely

A handwritten signature in black ink, appearing to read 'L. Macdonald', written in a cursive style.

Lindsey MacDonald

Chair

University of Canterbury Human Ethics Committee

University of Canterbury Private Bag 4800, Christchurch 8140, New Zealand. www.canterbury.ac.nz

F E S

April , 2016

Tēnā koe,

Gargi Sharma Thapaliya

Re:

This letter is written on behalf of the Ngāi Tahu Consultation and Engagement Group. In terms of your information provided we believe that this project is of great potential, value and importance.

The responses in the forms are well considered and the researchers are clear about how they ought to take participants' (cultural) needs into account.

Thank you for engaging with the Māori consultation process. The process strengthens and enlarges the network of support for your work. Feel free to contact the Māori research [advisors](#) for further advice should you need it. We wish you all the best with your current project and look forward to hearing about future research plans.

The Ngāi Tahu Consultation and Engagement Group would appreciate a summary of your findings on completion of the current project. Please feel free to contact me if you have any questions.

Nāku noa, nā



Nigel Harris

Acting Research Consultant Māori

Research and Innovation

Senior Projects Manager

Acting Māori Research Consultant

Office of AVC Māori

Te Whare Wānanga o Waitaha

Private Bag 4800

Otautahi Christchurch 8140

Aotearoa New Zealand

Phone +64 3 364 2987 ext 6120

[NTRC Website](#) | [UC Maps](#) |

[cellphone 0273950134](#)

nigel.harris@canterbury.ac.nz

Approval mail from CDHB research office

Dear Gargi,

Many thanks for sending your TKW consultation letter through to us. We now have all necessary documentation and, consequently can confirm that project **“A Cross sectional Survey of people with stroke, their family members and MDT Health professionals regarding the value of the information booklet and life after stroke: a guide for people with stroke and their families ”** has CDHB Locality Authorisation.

We would ask that you inform us about outputs/publications and the outcome from your project.

All the best for the project. Please don't hesitate to get in touch if we can assist further.

Kind regards

Liz

Liz Reeder, PhD | CDHB Research Advisor

Level 5 Christchurch School of Medicine, 2 Riccarton Ave, PO Box 4345, Christchurch Mail Centre, Christchurch 8140, New Zealand |

Ph: 03 364 1513 DD 81513 |

<http://www.otago.ac.nz/christchurch/research/researchoffice/>

Approval from the Stroke Foundation

RE: about the research

Tuesday, 26 January, 2016 11:33 AM

[Mark as Unread](#)



From:

"Fraser Pettigrew" <fraser.pettigrew@stroke.org.nz>

To:

"Gargi Sharma" <gargisharma91@yahoo.com>

Hello Gargi

Sorry it has taken me a while to get back to you. As I said in my very first email the Stroke Foundation has absolutely no problem with you using Life After Stroke for your research project and indeed we would be delighted to see the results. You may take that from me as official approval on behalf of the Stroke Foundation.

Kind regards

Fraser